IMPRESS Health 2

# Phase 1 Anglo-French Research Report on the IMPRESS Health 2 (Interreg IVA Channel Programme) Project 4282

## Understanding factors behind the late testing and diagnosis of HIV


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# Contents

## 1.0 Introduction: HIV in Europe

According to WHO and UNAIDS estimates, around 2.3 million people were living with HIV in the European region at the end of 2010 (UNAIDS, 2012; WHO, 2011). More than 131,000 new HIV infections were reported in Europe and central Asia in 2012, with 29,000 being diagnosed in the European Union and European Economic Area (EC Europa, 2014). Notwithstanding variations in the accuracy of reporting procedures from country to country, the estimated prevalence for adults ranges from as low as <0.1% in Malta, Germany and Finland, with the highest recorded prevalence in Estonia (1.3%), followed by Ukraine (0.8%), Portugal (0.7%), Latvia (0.7%) and Moldova (0.5%), although figures are not available for the Russian Federation or Uzbekistan (European Centre for Disease Prevention and Control, 2011). Within the EU, the highest prevalence of HIV infections are found in Estonia, Portugal, and Latvia, as indicated in the table below:

**Table 1: HIV Prevalence in the European Union for 2011**

| Country | Number of people with HIV/AIDS | Percentage prevalence in adults | Number of women with HIIV/AIDS | Number of AIDS related deaths |
|---|---|---|---|---|
| Austria | 18,000 | 0.45 | 5, 200 | <100 |
| Belgium | 20,000 | 0.35 | 5,700 | <100 |
| Bulgaria | 3,900 | 0.1 | 1,100 | <500 |
| Denmark | 6,200 | 0.2 | 1,600 | <100 |
| Croatia | 1,200 | <0.1 | <500 | <100 |
| Czech Republic | 2,100 | <0.1 | <1,000 | <100 |
| Republic of Cyprus | no data | no data | no data | no data |
| Estonia | 9,900 | 1.3 | 3,100 | <500 |
| Finland | 2,900 | 0.1 | <1,000 | <100 |
| France | 160,000 | 0.4 | 46,000 | 1,300 |
| Germany | 73,000 | 0.1 | 11,000 | <500 |
| Greece | 11,000 | 0.2 | 3,300 | <200 |
| Hungary | 4,100 | 0.1 | 1,300 | <100 |
| Republic of Ireland | 7,800 | 0.3 | 2,400 | <100 |
| Italy | 150,000 | 0.4 | 49,000 | <1,000 |
| Latvia | 9,100 | 0.7 | 2,800 | <1,000 |
| Lithuania | 1,500 | 0.1 | <500 | <1,000 |
| Luxembourg | <1,000 | 0.3 | <500 | <100 |
| Malta | <500 | 0.1 | <100 | <100 |
| Netherlands | 25,000 | 0.2 | 7,500 | <200 |
| Poland | 35,000 | 0.1 | 9,900 | <200 |
| Portugal | 48,000 | 0.7 | 14,000 | <200 |
| Romania | 16,000 | 0.1 | 4,700 | <500 |
| Slovakia | <500 | <0.1 | <200 | <100 |
| Slovenia | <500 | <0.1 | <200 | <100 |
| Spain | 150,000 | 0.4 | 35,000 | <1,000 |
| Sweden | 9,100 | 0.2 | 2,700 | <100 |
| United Kingdom | 94,000 | 0.3 | 29,000 | >500 |

(http://www.avert.org/european-hiv-aids-statistics.htm accessed 26/22/14)

Effective antiretroviral treatments have existed for some years now, but there is still no definitive cure nor a preventive vaccine for HIV. Current public health policy in relation to HIV is therefore focused on prevention and early detection since early diagnosis improves treatment options and increases life expectancy to near normal levels in those diagnosed quickly enough (Carricaburu and Ménoret, 2004; Chadborn, 2006). Without antiretroviral therapy however, the viral infection leads to immune deficiency with severe complications, and worsens comorbidities. Prevention and early diagnosis are also essential in slowing down its transmission within the general population. Early antiretroviral treatment is associated with the reduction of the ability to transmit the virus, and is now considered as part of prevention, hence the European Commission argue that, *'sexual and reproductive health outcomes are important measures of the general health and social well-being of a population'* (European Communities, 2008).

**1.1 HIV in the UK**

In spite of these efforts, the number of people living with HIV in the United Kingdom had risen to an estimated 98,400 by the end of 2012 (Public Health England, 2013). Approximately 20% of these people will not know that they are infected, and therefore risk transmitting the virus to others. In addition, almost half (47%) of the 6,360 people newly diagnosed with HIV that year were identified at a late stage, defined as having a CD4 count <350 cells/mm³ within three months of diagnosis, and consequently less likely to benefit from the full effects of newer antiretroviral therapies.

In the following year, 4,477 men and 1,522 women were newly diagnosed with HIV in the UK, a gender ratio of 3:1. Two thirds of male diagnoses were attributable to men who have sex with men, a proportion which has remained relatively stable in the last decade. The number of heterosexuals being diagnosed with HIV declined slightly, due in part to a decrease in immigration from countries where HIV in the heterosexual population is more prevalent (Public Health England, 2014). Seventy percent of new diagnoses occurred in those aged 25-49 years but it is interesting to note that 1 in 6 new diagnoses occurred in people over the age of 50 years with a smaller proportion being diagnosed in those aged between 15 and 24 years.

Older age has also been associated with late presentation in a number of studies reviewed by Mukolo et al (2012) as borne out by the latest figures from Public Health England (2013). These demonstrate that 63% of adults diagnosed with HIV in 2012 were over 50 years of age in comparison to 44% of those diagnosed aged 49 or less. Low socio-economic status, immigration status, poor literacy and lower educational attainment have also been correlated with a higher risk of late diagnosis. These suggest that stigma, lack of knowledge and poor understanding of HIV risk factors continue to impact upon early testing in many sectors of society, and a greater understanding of these issues is crucial to the development of effective public health strategies and testing programmes aimed at increasing the early uptake of HIV testing amongst each of these groups as well as men who have sex with men (Mukolo et al, 2012).

Ninety-two percent of the people living with HIV in the UK live in England, and almost half of these diagnoses (49%) are in London (Public Health England, 2014). New diagnoses among men who have sex with men also reached an all-time high in 2013, the majority being in London (Public Health England, 2013). Although men who have sex with men continue to be at higher risk of HIV infection overall, individuals from other groups are more likely to present later than men who have sex with men for HIV testing and subsequent diagnosis (Johnson et al, 2010). As a consequence, heterosexual

men are almost twice more likely to be diagnosed later with HIV than men who have sex with men (65% versus 34%), and the corresponding figure for heterosexual women is also higher at 57% (Public Health England, 2013). The figures for late diagnosis were also higher in comparison to men who have sex with men amongst black African men (66%), black African women (61%), black Caribbean women (66%), black Caribbean men (47%), white women (44%) and white men (47%) in 2012 (Public Health England, 2013).

Current policies in the UK tend to target individuals who are deemed to be at 'high risk' of being infected. For example, the Terrence Higgins Trust only provides free postal HIV test kits to African people or gay or bisexual men who live in England (Terrence Higgins Trust, 2013). These fourth generation HIV test kits can detect HIV as little as four weeks after infection, and have a key role to play in preventing the onward transmission of the virus. However, Mukolo et al (2012) express concerns that targeted HIV prevention and testing interventions such as this do not specifically target heterosexual males, meaning that they are provided with fewer opportunities for HIV testing and diagnosis than men who have sex with men, injecting drug users and women attending antenatal care where HIV testing is routinely undertaken. With privately available HIV testing kits costing as much as £99 in the UK, it is essential that cost does not become an issue for anyone wanting to know their status and the availability of free, confidential testing is better advertised to everyone.

### 1.2 HIV in France

The *Bulletin épidémiologique hebdomadaire* (Institute of Health Surveillance/L'Institut de veille sanitaire, 2012) shows that France had 6,372 new diagnoses of HIV; almost exactly the same number as that recorded in the UK that year. Its prevalence remains slightly higher than the UK however, and there is concern that decreases in the number of HIV infections in the first decade of the century are now being reversed with HIV transmission increasing continuously in the population since 2007 (Lert and Pialoux, 2010). Forty-two percent of these new diagnoses were in men who have sex with men, 23% occurred in women and 15% in heterosexual males born outside the country. Of the remainder, 10% occurred in French-born heterosexual males and 7% in French-born heterosexual women, with intravenous drug users accounting for an additional 1% (Institute of Health Surveillance, 2012).

In common with the UK, HIV infections amongst men who have sex with men continue to increase (Lert and Pialoux, 2010; Institute of Health Surveillance, 2012), although like their UK counterparts, they are also likely to be diagnosed earlier than heterosexuals due to their requesting more frequent and regular testing (32% versus 18%). Consequently, 62% of men who have sex with men in France were diagnosed with a CD4 count of 351 cells/mm$^3$ or higher, with many being diagnosed before any signs or symptoms of infection become apparent. More encouragingly, 21% of these men were estimated to have been diagnosed within one month of infection (Institute of Health Surveillance, 2012) which suggests that important messages about early testing and diagnosis are beginning to reach this community if not others, such as the 56% of people infected through heterosexual intercourse, of which those over 50 years are far more likely to present in the later stages of illness.

HIV is more commonly diagnosed in people between 25 and 49 years of age, with 70% of all new diagnoses in 2012 falling within this category (which includes men who have sex with men). As in the UK, this cohort of people are more likely to be tested and diagnosed early in comparison to older individuals, and concern has been raised in particular about the number of heterosexual men over

the age of 50 who do not present for regular testing and are routinely diagnosed much later in the disease process. Concern has also been expressed about regional disparities; with 42% of new diagnoses occurring in the Ile-de-France region which includes Paris, although this is slightly less than the 49% of new UK diagnoses which occur in London. This region is followed by the overseas territories of Guyana, Guadeloupe and Martinique, and the region of Provence-Alpes-Côte-d'Azur.

Unlike the UK, where sexual health clinics are often regarded as the first line of defence against HIV, responsibility for HIV prevention and testing in France is primarily as the responsibility of 'medecins generalistes' (General Practitioners). Figures from the *Bulletin épidémiologique hebdomadaire* (Institute of Health Surveillance, 2012) show that 76% of HIV tests were initiated by GPs in France which is likely to be a much higher percentage than those initiated by GPs in the UK. As in the UK however, concerns have been expressed in France about the capability and willingness of primary care practitioners to engage in vital health promotion and protection work in relation to HIV risk reduction and testing in those groups not deemed to be at high risk of HIV, particularly GPs, who may fear that such questions might seem impertinent (Souville, 2002). Notwithstanding this, the French public health authorities explicitly recommend that primary health care professionals offer an HIV test to all patients between 15 and 70 years of age, irrespective of their risk of exposure to HIV (Ministry of Health and Sports, 2010), and it has been suggested that GPs are 'key players' in the fight against HIV by Souville (2002).

France has the highest number of people diagnosed with AIDS in Western Europe, with an estimated 40,000 people living with AIDS in 2012 and an additional 800 cases per year (Institute of Health Surveillance, 2012). It is not surprising that it also has the highest number of AIDS deaths, with 2,000 estimated deaths in 1999, 800 deaths in 2001, 1,000 deaths in 2003, 1,600 deaths in 2007 and 1,700 deaths in 2009. In 2011, it was estimated that 1,300 deaths were attributable to AIDS, although this is likely to be an underestimate as many other reported causes of death (such as those from certain cancers, pulmonary infections etc.) may be directly attributable to the condition which remains undiagnosed in some cases (http://www.avert.org/european-hiv-aids-statistics.htm accessed 18/12/14). In Picardy in 2013 the number of newly diagnosed HIV positive people was estimated by the Institute of Health Surveillance/l'institut de veille sanitaire (2014) at 96 cases. Males and those born overseas were particularly affected accounting for 69% and 46% of those cases respectively (l'agence régionale de santé de Picardie et du conseil régional de Picardie, 2014).

### 1.3 The rationale for early testing and diagnosis

Individuals who are diagnosed early can gain greater benefit from antiretroviral therapy, and as a consequence, early testing can contribute to a near-normal lifespan for most HIV positive patients (Castilla et al, 2002; Chadborn, 2006). Late presentation and diagnosis are clearly detrimental to long-term health status however, and are associated with increased morbidity and mortality as well as the potential for those infected with the virus to transmit it to others (Public Health England, 2013). In addition, it has been demonstrated that individuals diagnosed late with HIV also incur significantly higher medical costs during the course of their lives than those diagnosed and subsequently treated earlier (Krentz et al, 2004). Public Health England (2013) found that over a quarter (28%) of people diagnosed with HIV in 2012 were already severely immunocompromised, defined as having a CD4 cell count <200 cells/mm$^3$ at diagnosis, and likely to require longer and more frequent admissions to hospital than those diagnosed earlier.

### 1.4 Suggested reasons for late presentation

The reasons for late presentation, testing and diagnosis are many and varied (Yazdanpanah et al, 2010). Studies suggest that barriers exist at individual, societal, medical, and public policy levels, and each of these must be better understood if rates for early detection are to be improved (Mukolo et al, 2012). Mukolo et al's (2012) review of the literature suggests that living in a region with a lower known prevalence of HIV increases the risk of late diagnosis, possibly because the risk of infection is perceived to be lower or there is a greater stigma associated with the condition in such areas (Adler et al, 2010). Cognitive appraisal of actual or potential risk factors also tend to influence presentation and diagnosis timelines, with denial or cognitive dissonance being identified as exacerbating factors in a number of studies (Yazdanpanah et al, 2010; Hanf et al, 2011; Dowson et al, 2012). Similarly, fear of the consequences of a positive HIV test, including anticipation of pain, illness, premature death, stigma, discrimination and diminished economic and wage-earning capacity may all contribute to an individual's prevarication with regard to HIV testing (Hanf et al, 2011; Mukolo et al, 2012; Dowson et al, 2012). These assume that the individual is aware that they have been exposed to HIV risk whereas many may not in fact be aware of this at all.

Mukolo et al's (2012) review highlighted that presentation decisions were sometimes made within social contexts characterised by hostility towards people living with HIV and AIDS, the stigma associated with stereotypical assumptions about those most at risk of infection, knowledge deficits regarding relative risk, as well as unusual or unhelpful beliefs about the causes of HIV, individual responsibility for infection, and attitudes about human sexuality and behaviour. Stigma has long been associated with an HIV diagnosis as identified by Silverman (1989), Weitz (1989), Pollak (1990), Siegel and Krauss (1991) and Carricaburu and Pierret (1995), but increasingly, fear of disclosure and subsequent ostracisation within close-knit social communities has become a common reason for not being tested in some migrant populations due to fear of economic, legal or immigration difficulties (Yazdanpanah et al, 2010). In particular, this study showed that specific barriers exist for many migrant populations, including the stigma associated with HIV positive status within African communities in the UK, the prevailing belief that it is a life-threatening condition, anxiety that the results of an HIV test may not remain confidential, and that diagnosis of HIV infection would either reduce an individual's chance of success when applying for permanent residence or bring them to the attention of immigration services for questioning or deportation (Yazdanpanah et al, 2010).

Evidence suggests that many opportunities to identify and test those at risk in health facilities are being missed (Sullivan et al, 2005; Sudarshi et al, 2008). Potential barriers include lack of time and uncertainty about consenting and pre-test counselling requirements, logistical barriers such as competing priorities, lack of knowledge and language barriers. Deficits in the knowledge, education and training of physicians for this task have also been identified, and they may therefore be unaware of which groups and behaviours indicate a high risk for HIV infection and lack confidence to suggest that a test may be necessary. Wohlgemut et al (2012) warn against stereotyping 'at risk' patients however, as 20% of diagnoses in their study occurred in those without a clear transmission risk, suggesting that early diagnosis is complicated by rapidly changing socio-demographic factors and subtle shifts in at risk HIV populations in the UK. In particular, opportunities to identify HIV infection in those who are older, white British, and those from socially deprived communities are often missed.

### 1.5 Strategies to increase the uptake of early HIV testing

Many studies have suggested that there is a need to develop interventions that increase HIV testing and facilitate earlier entry into care, such as routine screening in healthcare and non-clinical settings for those at risk of HIV (Girardi et al, 2007; Yazdanpanah et al, 2010; Garcia de Olalla et al, 2011; Camoni et al, 2013). Branson et al (2006) suggest that it might be feasible to include HIV testing as a routine part of healthcare practice for all adults and adolescents aged 13-64 years as proposed by the United States Centers for Disease Control and Prevention, whilst guidance from the World Health Organisation (2007) recommends the use of an 'opt-out' approach; including the provision of health care provider-initiated testing aided by simplified pre-test information and improved health counselling facilities. In this model, individuals attending healthcare settings would routinely be offered a recommended HIV test although they would be free to decline such a test.

It is clear from the evidence that further work needs to be done to raise awareness of HIV risk and transmission together with the benefits of early testing and diagnosis both for the general public and healthcare professionals. Current examples of health promotion interventions include National HIV Testing Week (which takes place annually in the UK) and World AIDS Day. Evidence also supports the use of mass media campaigns to raise awareness and increase the uptake of testing and signpost concerned individuals to appropriate services. There is an emerging evidence base for the delivery of targeted HIV prevention messages using the internet and social media since these technologies could reach far deeper into certain target populations (Rashbrook, 2013), and may also be used to de-stigmatise HIV/AIDS by emphasising the positive benefits of testing (Mukolo et al, 2012).

Dowson et al (2012) suggest that a more proactive approach by healthcare professionals, including general practice, may result in earlier testing by making it more convenient and accessible. Other suggestions include improving recognition of potential indicators of infection amongst physicians and other healthcare providers (Yazdanpanah et al, 2010), continuing education and the use of financial incentives to motivate them to discuss HIV risk with their patients (Lo et al, 2011; Dowson et al, 2012). Pereira et al (2011) suggest that since nurses are in the frontline in 'the war against the HIV pandemic', they too must improve their knowledge and intensify their efforts to support and encourage people to have an HIV test. Schwarz et al (2011) meanwhile, asserts that public health messages to increase HIV testing should include up-to-date information about the ways in which HIV can be transmitted, the fact that effective, tolerable and low cost medication is readily available for HIV; and that early diagnosis significantly improves an infected individual's health outcomes.

### 1.6 Rationale for the study

The UK region of Kent and Medway and the French region of Picardy have identified similar trends in late HIV diagnosis for their respective local populations, of which approximately half are classified as late diagnoses. Patients diagnosed late are ten times more likely to die within a year, so the importance of improving the uptake of early HIV testing is clear for both regions. They also have similar patient demographics, with the majority of new diagnoses occurring in migrants of Black African descent or men who have sex with men. They also have similar rates of late diagnosis for older, white heterosexual people, a group which is seldom considered likely to have or to transmit HIV. It is clear that efforts to increase early uptake of screening in both regions have had little effect to date, so research to elicit reasons for late referral and testing, and develop new interventions to promote early testing are warranted. A successful application for funding was therefore made to the Région Haute-Normandie Interreg body and funding received to conduct such research.

## 2.0 Methodology

The main aim of the project, which is still ongoing, is to improve the uptake of HIV screening and reduce the proportion of late diagnoses in Kent and Medway in the UK, and Amiens and Creil in Picardy, France by identifying reasons for late presentation and developing interventions aimed at increasing earlier testing and diagnosis in both countries. The broad aims and objectives are to:

- conduct a comprehensive literature review of previous work undertaken in the field of late testing and diagnosis of HIV
- conduct a comprehensive study to understand why individuals in both regions typically test late for HIV
- develop an intervention or interventions to support changes in knowledge, health beliefs and/or behaviour in order to improve rates of early diagnosis of HIV in both regions
- evaluate the impact of these interventions and disseminate the findings to others

These aims are broadly commensurate with the three phases of the project, the final phase of which is due to be completed by the end of March 2015. Phase one describes the conduct of a mixed methods study (Creswell and Plano-Clark, 2011) including the conduct of a comprehensive literature review to evaluate the current evidence base and inform the development of an empirical study to understand why individuals in both regions typically test late for HIV. This review was completed during the summer of 2013 and is currently being submitted for publication in a peer-reviewed scientific journal.

Findings from the literature review were then used to inform the development of the retrospective analysis of patient clinical data for a five year period to determine whether specific demographic, individual or illness related characteristics have any bearing upon a person's decision to request an HIV test and the timing of this decision. The retrospective analysis of patient clinical data was completed early in 2014, and the findings of this analysis were then triangulated against data from 149 semi-structured, qualitative interviews conducted with 82 patients and 67 healthcare professionals (the need to interview both being indicated by the initial literature review) across both countries. These elicited information about knowledge, beliefs, attitudes, decision making processes and consequent health behaviours from the perspectives of both patients and healthcare professionals in France and the UK and constituted phase 1 (the research phase) of the project.

This report outlines findings from this first phase of the project carried out in both the UK and France between October 2013 and March 2014. It contains findings from the retrospective review of patients' clinical data, and data from the semi-structured interviews with patients and healthcare professionals. These findings have been used to inform the development of a programme of clinical, health education, social media and professional education interventions to encourage earlier testing and diagnosis of HIV which are currently being implemented, and the success of which will be evaluated in the final (evaluation) phase of the project between January and March 2015.

### 2.1 Aims and objectives for phase 1 of the project

The aim of the first phase of the project covered by this report was to identify reasons or statistical correlates which might explain the continued late diagnosis of so many people in Kent, Medway, Amiens and Creil with HIV. The following objectives were therefore set for phase 1 of the project as follows:

- Retrospectively review the clinical data of patients diagnosed with HIV for a period of five years (from the end of 2008 to the end of 2013) in Kent, Medway, Amiens and Creil to identify variables correlated with late diagnosis such as gender, age, occupation etc.
- Recruit and interview a target number of HIV positive patients who had been diagnosed within the same five year period to elicit their knowledge, understanding, views, and personal experiences of HIV testing and potential barriers which may have prevented them seeking an earlier HIV test
- Recruit and interview a target number of healthcare professionals in both France and the UK to elicit their knowledge, understanding, views, and personal experiences of HIV testing and potential barriers which may in their opinion prevent patients from seeking an earlier HIV test
- Analyse the data and make recommendations for a joint programme of clinical, health education, social media and professional education interventions to encourage earlier testing and diagnosis of HIV in both countries which would help to increase the uptake of early HIV testing.

**2.2 Ethical approval and considerations**

Ethical approval for the French arm of the project was gained from the comité de Protection des Personnes en recherche biomédicale of the Centre Hospitalier Universitaire Amiens Picardie which gave access to patients, staff and medical records at both data collection sites in Picardy. Ethical approval for the UK arm of the project was first obtained from the NHS National Research Ethics Service Committee North East (Newcastle and North Tyneside). Local research applications for letters of access where then obtained from each of the research and development committees of Kent Community Health NHS Trust, East Kent Hospitals University NHS Foundation Trust, Maidstone and Tunbridge Wells NHS Trust and Medway NHS Foundation Trust for clinical patient data and permission to interview NHS staff, the RM&G Consortium for permission to conduct GP interviews, and the Research and Governance Office of Canterbury Christ Church University for permission to interview trainee GPs.

Given the potentially sensitive nature of the interviews for both patients and staff, these were conducted by suitably trained research professionals working for Canterbury Christ Church University in the UK, or research assistants (attachés de recherche clinique) from the clinical research centre at the Centre Hospitalier Universitaire Amiens Picardie and the Groupe Hospitalier Public du Sud de l'Oise. Psychological support for patients and staff were made available in France by partners working for the AIDES (www.aides.org), a community health association which directly involves people at risk of or infected by HIV or hepatitis in prevention, treatment and support initiatives, and by staff from the local IREPS (L'Instance Régionale d'Éducation et de Promotion de la Santé) charity. UK respondents were offered the opportunity for follow-up counselling or psychological support from Agatha Benyera, a qualified counsellor employed within the Faculty of Health and Wellbeing at Canterbury Christ Church University, who is also a counsellor for Health Action Charity Organization (HACO) a community organisation proving support and confidential advice to Black Africans and minority ethnic groups in England, and specifically, Medway. UK respondents were also provided (via the Participant Information Sheets) with the contact details for

the relevant team within each Trust should they like to take independent advice on whether to participate.

**2.3 Inclusion/exclusion criteria and sampling for patient interviews**

All HIV positive patients diagnosed within the participating centres within the last five years on commencement of the study were eligible for interview. Patients were approached by their clinicians and asked if they would like to take part. Patient information sheets and confidential contact details of the research teams were also provided so that patients could contact them if the wished to be interviewed. Given the sensitive nature of the research area a stringent consenting process was enforced to ensure that individual clinicians did not know which of their patients had been interviewed unless patients opted to reveal this to them. This resulted in 37 patients agreeing to be interviewed in the UK and 45 being interviewed in France were potential interview candidates were identified from patient case notes. These were contacted by Astrid Debuysscher in Amiens and Francesca Masson in Creil who asked them if they would agree to be interviewed. Approximately 40% refused to be interviewed although the reasons for this were not elicited.

**2.4 Inclusion/exclusion criteria for healthcare professional interviews**

Interviews with healthcare professionals were conducted face to face or by telephone if preferred. Notwithstanding this flexibility and offers to interview staff at a time of their choosing, the recruitment of professional respondents was disappointingly low in all three settings. The greatest representation from a single professional group in the UK came from General Practitioners (5), followed by specialist HIV social workers (3), and GUM consultants (2), with single respondents from other areas and specialities. Many practitioners known to care for HIV positive patients in acute clinical areas were identified via a 'snowballing' recruitment strategy whereby HIV specialists emailed clinicians they regularly referred patients onto. Many failed to respond to email requests to take part in the study whilst others failed to respond to a maximum of three reminder emails sent by the project administrator after an initial expression of interest was received. Others indicated that they could only be available for interview after the 30$^{th}$ March when letters of access allowing access to the research centres expired. One potential respondent wished to be interviewed whilst driving in his car which the team refused to do on the basis of legal and road safety issues. It was also disappointing that high levels of interest shown by a group of GP trainees during one of their training days at the University failed to result in a single interview with someone from this group in spite of the three reminder emails sent by the project administrator to those who initially expressed an interest in being interviewed.

As a consequence, 16 healthcare practitioners only were interviewed for study the in the UK. This number consisted of 5 General Practitioners, 3 Specialist Social Workers, 2 Genitourinary Consultants, 1 Clinical Nurse Specialist, 1 Sexual Health Nurse, 1 Specialist HIV Pharmacist, 1 Obstetrics and Gynaecology Consultant, 1 Nephrology Consultant, and 1 Gastroenterologist. The initial target for interviews with GP 'specialists' was met in full (5 interviews) although it proved difficult to identify 'poorly performing' practices directly. Those GPs who did come forward for interview were exceptionally well-informed, enthusiastic and committed to the testing, diagnosis and care of HIV patients, so were clearly in the vanguard of their professional group and not representative of the somewhat negative feedback about GP involvement in HIV testing, diagnosis and management made by other healthcare professionals and patients. Surprisingly, there was a high degree of convergence between healthcare professional and patient opinion regarding HIV

testing, so for the most part, the discussion and recommendations are based upon the patients' experience and opinions supplemented by those of healthcare professionals.

In France, 51 general practitioners were contacted for interview directly since it was decided that this professional group had primary responsibility for HIV prevention and testing, and requests for testing from/by another specialist are generally rare.[1] Many refused to take part in the study either because they had no experience of referring a patient for HIV testing or they had inadequate time to conduct the interview.

### 2.5 Conduct of the patient/healthcare professional interviews

Interviews in the UK were conducted by Sharon Manship, Matt Hart and Stephen O'Connor from Canterbury Christ Church University with Matt Hart conducting most of the interviews in Maidstone and Tunbridge Wells, Sharon Manship conducting the majority of interviews in Medway, and Stephen O'Connor and Sharon Manship conducting interviews for Kent Community Health NHS Trust (including those carried out at premises owned by the East Kent Hospitals University NHS Foundation Trust). The small size of the interview team had no bearing on recruitment to the study and may be regarded a strength of the study since it provided greater consistency in the approach taken by each interviewer and increased inter-rater reliability. English versions of the interview topic lists for both patients and healthcare professionals are provided in Appendices 1 and 2 at the end of the report. In France, 3 research assistants from the research centre of the Centre Hospitalier Universitaire Amiens Picardie conducted all of the interviews of the patients. Dr Christof Kreutz, from the research centre conducted the GP interviews.

### 2.6 Analysis of the data

In both countries, data were transcribed verbatim prior to initial analysis which followed three stages. The first consisted of thoroughly reading each interview while noting general themes and comments. This involved reading the interview in detail, paragraph by paragraph, and selecting extracts that appeared pertinent. Next a horizontal analytical reading took place, which involved establishing analytical categories from each interview (Blanchet and Gotman, 1992) by inserting the text into NVivo 10 software and using this to identify as many codes (or nodes in NVivo parlance) as seemed relevant. The third stage of analysis consisted of a vertical reading of the data to develop broader categories from these nodes and identify illustrative examples for each. The coding of data therefore moved from initial coding based on the broad topics covered by the interview schedule to a more discrete analysis of the richer information provided by respondents in each interview which were used to generate theoretical categories from the data which would be helpful in developing interventions for phase 2 of the study.

### 2.7 Issues of reliability, validity and rigour

The face validity of the interviews was good since there was a high level of convergence in the information derived from different respondents by different interviewers, even when differences in personal circumstances and experience were taken into account. The intrusion of social desirability variance seemed low with respondents giving open, candid, and at times, very explicit accounts of their knowledge about HIV risk factors, their experiences of HIV testing, and the social, psychological and physical sequelae of a positive test result. They were also forthcoming in their advice and opinions as to how screening and the uptake of HIV testing could be improved.

[1] Personal communication, Prof. Jean-Luc Schmit (Centre Hospitalier Universitaire Amiens Picardie)

A high degree of data saturation was also observed by the time that most patient or healthcare professional interviews had been concluded. Nevertheless, these continued to ensure that no additional or divergent information would emerge unexpectedly from other of the healthcare settings in which the research was being conducted. We are confident that with so large a number of both patient and healthcare interviews, that a significant amount of rich data has been gained, and that respondent experiences across all participating centres in both countries are broadly similar as indicated by the similarities in text and meaning derived from interviews on both sides of the English Channel. The experiences of respondents (both French and English) seem to be very similar, which speaks to the commonality of human experience when threatened with a clinical and existential challenge as significant as HIV. As such, we are sure they provided a sound basis on which theoretical generalisations and concrete recommendations for specific interventions or changes in practice to be tested in phases 2 and 3 of the project can be made.

## 3.0 Findings from review of clinical data

The following data were collected from patient records in each of the participating centres:

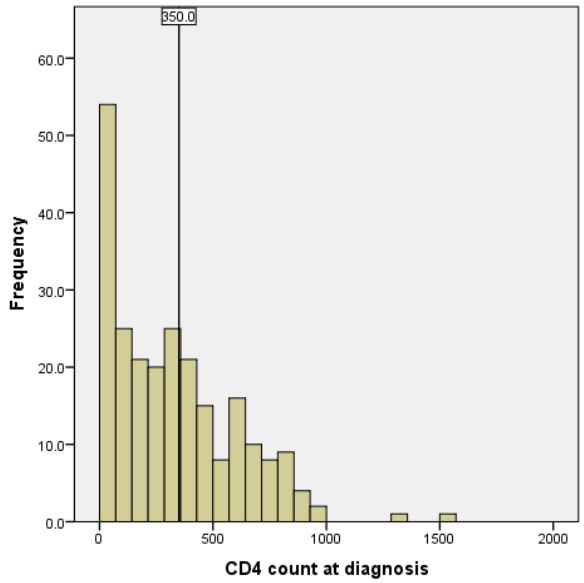
- Age at first positive HIV test
- Gender
- Ethnic origin (UK only)[2]
- Place of birth
- Highest level of education attained (UK only)
- Occupational status
- Most likely transmission route
- Place of HIV diagnosis (UK only)
- Co-morbidities at the time of HIV diagnosis

Details were requested on HIV/AIDS defining illnesses recorded at the time of diagnosis, together with any other non-HIV defining illnesses. Few data were available on the details of current or most recent employment in the medical notes, and in some cases the occupational status listed appeared inconsistent with job descriptions and/or declared educational level. In some cases, those in full-time education were incorrectly listed as 'unemployed', so for this reason, data on employment and educational status were therefore excluded from the report for both countries.

### 3.1 Patient CD4 counts across and within study settings

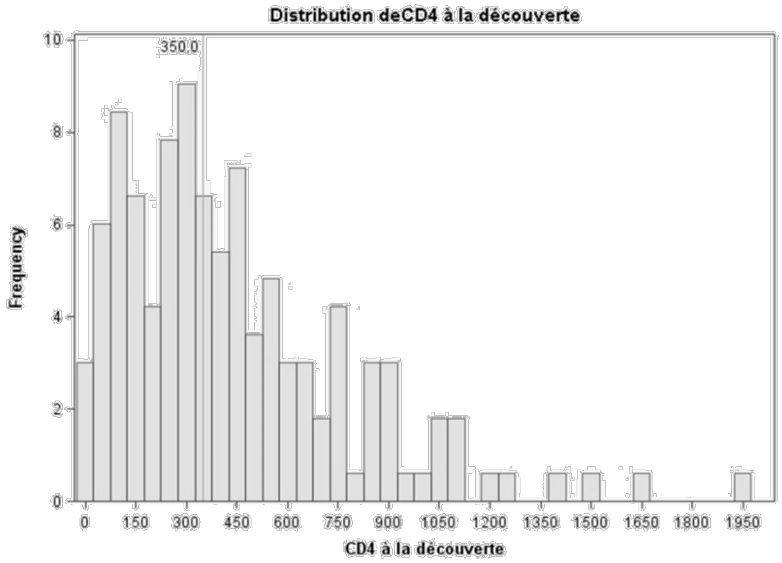
CD4 counts at first diagnosis were provided from each of the centres involved in the study for a total of 240 patients in the UK and 166 patients in France. Figure 1 shows the distribution of CD4 levels in the UK and figure 2 shows the same data for France.

**Figure 1: HIV positive patients' CD4 counts at initial diagnosis in the UK (Kent and Medway)**




[2] There are differences in the legality/social acceptability of recording ethnic or racial origin in France and the UK so whilst membership of standard groups such as White British, Afro-Caribbean, Asian etc. was collected in the UK, only the place of birth (i.e. Mainland France or départements et territoires d'outre-mer versus elsewhere) were collected.

**Figure 2: HIV positive patients' CD4 counts at initial diagnosis in France (Amiens and Creil)**




The cut-off criterion for late diagnosis is included in both histograms. One hundred and forty-five (60.4%) UK patients had CD4 counts on diagnosis of 350 or less, and 95 (39.6%) had CD4 counts greater than 350. There was no significant difference in the levels of late diagnosis between different hospitals or clinics diagnosing and treating HIV positive patients in the UK or in France, but there was a difference between the two countries. In France, 83 (50.0%) of the 166 patients whose notes were reviewed had CD4 counts on diagnosis of 350 or less. This is lower than the 145 (60.4%) patients diagnosed late in the UK as demonstrated by Table 2 below.

**Table 2: CD4 status on diagnosis by participating centre (UK and France)**

| | | | CD4 count ≤350 | CD4 count >350 | Total |
|---|---|---|---|---|---|
| **UK** | **Maidstone and Tunbridge Wells** | Number | 42 | 23 | 65 |
| | | Percentage | 64.6% | 35.4% | 100.0% |
| | **Kent Community Health NHS Trust** | Number | 66 | 53 | 119 |
| | | Percentage | 55.5% | 44.5% | 100.0% |
| | **Medway** | Number | 37 | 19 | 56 |
| | | Percentage | 66.1% | 33.9% | 100.0% |
| | **UK Totals** | **Number** | **145** | **95** | **240** |
| | | **Percentage** | **60.4%** | **39.6%** | **100.0%** |
| **France** | **Amiens** | Number | 49 | 47 | 96 |
| | | Percentage | 51.0% | 49.0% | 100.0% |
| | **Creil** | Number | 34 | 36 | 70 |
| | | Percentage | 48.6% | 51.4% | 100.0% |
| | **France Totals** | | **83** | **83** | **166** |
| | | | **50.0%** | **50.0%** | **100.0%** |

### 3.2 Analysis of variables by CD4 ≤350 versus CD4 >350

*3.2.1 Age at first positive HIV test*

It is clear that HIV infection is no respecter of age in either country. The mean age of UK patients at first test was 40, with a wide range from 19 to 81 years. The mean age was younger, 37 years for French patients with another wide range from 17 to 71 years. Table 3 shows national differences in age at first test for those diagnosed early and late in both countries whilst Figure 3 shows the distribution of age at first diagnosis for both sets of patients with the UK in the upper histogram and France in the lower. The distribution is bi-modal in the UK with peaks at 38 and 43 years, but this is likely to be a reflection of the moderate sample size and the units on the x-axis. Those patients diagnosed late in the UK were a little over four years older than patients diagnosed early (independent t = 2.89, p<0.005) whereas in France, those diagnosed late were six years older on average than patients diagnosed late in the UK (independent t = 3.66, p=0.0003) and unlike the UK, there was a single peak in infection at 37 years, three years younger than the UK.

**Table 3: Age at first test CD4 ≤350 versus CD4 >350**

| | | N | Mean | Standard Deviation |
|---|---|---|---|---|
| **UK** | **CD4 count ≤350** | 141 | 41.24 | 10.922 |
| | **CD4 count >350** | 94 | 37.11 | 10.475 |
| **France** | **CD4 count ≤350** | 83 | 39.67 | 10.28 |
| | **CD4 count >350** | 83 | 33.87 | 9.94 |

**Figure 3: Age at first test and diagnosis of HIV infection**

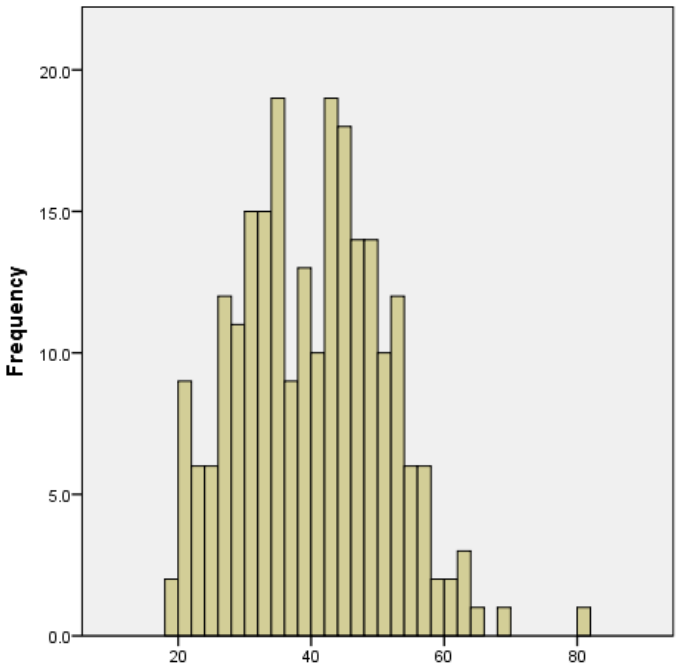
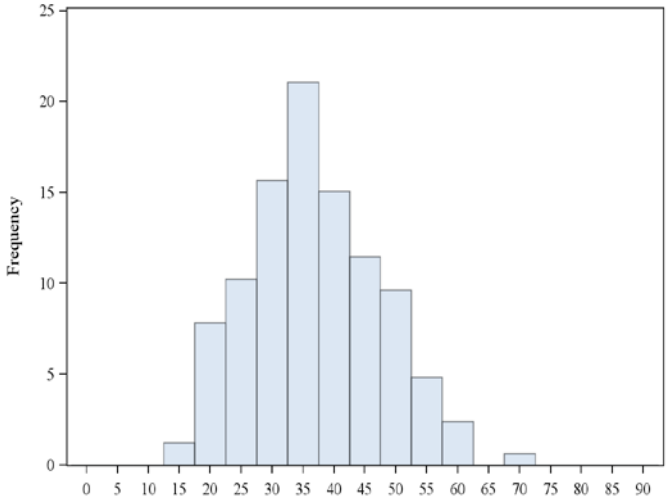


**Figure 3: Age at first test and diagnosis of HIV infection – ctd.**




The following sections present comparisons of the late and early diagnosed patient groups in relation to further patient characteristics with the exception of occupational status. Multiple categories are condensed as appropriate given the frequency of cases. Simple comparisons were made using the chi-squared test.

*3.2.2 Gender*

There was approximately the same number of men (89) in the sample as women (77) in France, whereas the number of men (162) was more than twice as great as for women (78) in the larger UK sample. Whilst the number of men diagnosed late was greater than women in both countries (92 in the UK and 42 in France), women were more likely to be diagnosed late in comparison to men in both countries with almost 68% of women in the UK and 53.3% of women in France diagnosed late. This difference is marginally significant in the UK (chi-squared 2.74, df1, $p<0.10$) but was not significant in France (chi-squared 0.6056, df1, $p=0.4365$).

**Table 4: Gender of patients CD4 ≤350 versus CD4 >350**

| | | | CD4 count ≤350 | CD4 count >350 | Total |
|---|---|---|---|---|---|
| **UK** | **Male** | Number | 92 | 70 | 162 |
| | | Percentage | 56.8% | 43.2% | 100.0% |
| | **Female** | Number | 53 | 25 | 78 |
| | | Percentage | 67.9% | 32.1% | 100.0% |
| | **UK Totals** | **Number** | **145** | **95** | **240** |
| | | **Percentage** | **60.4%** | **39.6%** | **100.0%** |
| **France** | **Male** | Number | 42 | 47 | 89 |
| | | Percentage | 47.2% | 52.8% | 100.0% |
| | **Female** | Number | 41 | 36 | 77 |
| | | Percentage | 53.3% | 46.7% | 100.0% |
| | **France Totals** | **Number** | **83** | **83** | **166** |
| | | **Percentage** | **50.0%** | **50.0%** | **100.0%** |

*3.2.3 Ethnic origin*

Most patients in the UK sample fell into two distinct ethnic groups: White British followed by Black British/Caribbean and Black African, with a very small number of patients in the remaining categories provided. The sample was therefore divided into White British and 'Other'. It is clear that ethnic background does have a bearing on late diagnosis with 70.2% in the minority ethnic groups of all backgrounds having CD4 counts of 350 or less at diagnosis compared with 53.0% in the white group (chi-squared 7.26, df1, $p<0.01$). As noted previously, data were not collected in France on ethnicity but place of birth instead due to legal and constitutional restrictions about the collection of data on ethnicity and religion.

**Table 5: Ethnicity of UK patients CD4 ≤350 versus CD4 >350**

| | | | CD4 count ≤350 | CD4 count >350 | Total |
|---|---|---|---|---|---|
| **UK only** | **White British** | Number | 71 | 63 | 134 |
| | | Percentage | 53.0% | 47.0% | 100.0% |
| | **Other** | Number | 73 | 31 | 104 |
| | | Percentage | 70.2% | 29.8% | 100.0% |
| | **UK Totals** | **Number** | **144** | **94** | **238** |
| | | **Percentage** | **60.5%** | **39.5%** | **100.0%** |

*3.2.4 Place of birth*

Data on place of birth for both countries showed that those born outside the UK or France were much more likely to be diagnosed late than patients born in those countries. Seventy-four (69.8%) of the patients diagnosed late in the UK were born outside the country whilst in France, 50 (58.8%) of those not born in the country were diagnosed late. Thus, the number of late diagnoses in patients born in either country were much lower than those born elsewhere (chi-squared 5.09, df1, $p=0.024$). It is difficult to draw firm conclusions about the reasons for these disparities, for example: whether language deficits, lack of knowledge, or difficulties accessing healthcare played a role in their genesis as they may also be due to lack of information or testing opportunities in their country of birth where the infection occurred in countries other than the UK or France. Moreover, some data on place of birth were missing from the patient records in both countries, which makes it impossible to speculate on the causes for this observation.

**Table 6: Place of birth of patients CD4 ≤350 versus CD4 >350**

| | | | CD4 count ≤350 | CD4 count >350 | Total |
|---|---|---|---|---|---|
| **UK** | **UK born** | Number | 71 | 62 | 133 |
| | | Percentage | 53.4% | 46.6% | 100.0% |
| | **Rest of world** | Number | 74 | 32 | 106 |
| | | Percentage | 69.8% | 30.2% | 100.0% |
| | **UK Totals** | **Number** | **145** | **94** | **239** |
| | | **Percentage** | **60.7%** | **39.3%** | **100.0%** |
| **France** | **French born** | Number | 33 | 47 | 80 |
| | | Percentage | 41.3% | 58.7% | 100.0% |
| | **Rest of world** | Number | 50 | 35 | 85 |
| | | Percentage | 58.8% | 41.2% | 100.0% |
| | **France Totals** | **Number** | **83** | **82** | **165** |
| | | **Percentage** | **50.3%** | **49.7%** | **100.0%** |

*3.2.5 Highest level of education attained (UK only)*

No information was available on the patient's highest level of education attainment in just over 40% of the UK case notes studied and no information was available at all from the patients' clinical records in France. In those UK patients for whom data were available, just over half (56%) had not progressed beyond compulsory secondary education. Of the remainder, 21% had completed further education and 21% higher education. Interestingly, those with only a secondary education had the lowest level of late diagnosis but the differences are only marginally significant (chi-squared 5.01, df2, $p<0.10$). However, the proportion of missing data available from staff recall in the UK and its total absence in the French data means that it is impossible to ascribe any significance or draw firm conclusions about the influence of formal education as a variable affecting early or late diagnosis with HIV. It unlikely moreover, that such detail would normally be found in a retrospective review of patient clinical data since information about this would not usually be elicited during a routine clinical consultation except for the fact that members of the clinical team knew their patients well enough to provide this information for almost half their patients.

**Table 7: Educational level of patients with CD4 ≤350 versus CD4 >350 in the UK**

| | | CD4 count ≤350 | CD4 count >350 | Total |
|---|---|---|---|---|
| **Compulsory secondary education** | Number | 40 | 38 | 78 |
| | Percentage | 51.3% | 48.7% | 100.0% |
| **Further education** | Number | 22 | 8 | 30 |
| | Percentage | 73.3% | 26.7% | 100.0% |
| **Higher education** | Number | 21 | 11 | 32 |
| | Percentage | 65.6% | 34.4% | 100% |
| **Total** | **Number** | **83** | **57** | **140** |
| | **Percentage** | **59.3%** | **40.7%** | **100.0%** |

*3.2.6 Occupational status*

Occupational status was recorded for only 216 of the 240 UK patients diagnosed within the 5 year period under review and 137 from a possible 166 patients in the French data set. Almost half the UK patients indicated that they were employed on a full-time basis and just over a quarter were unemployed. There were differences in the way that occupational status was classified in the French data where no distinction was made between full and part-time employment, and adults in full-time education were deemed to be not working and hence unemployed. This may account for more than half (78/137) of the French patients being classified as unemployed or in education, a far higher proportion that that reported in the UK, particularly if full and part-time employment in the UK are added together. These differences make it difficult to analyse data for this variable meaningfully. It would seem however, that employment status is unlikely to have any bearing on CD4 levels at diagnosis, and hence on whether people presented early or late for testing in either country.

**Table 8: Occupational status of patients with CD4 ≤350 versus CD4 >350**

| | | | CD4 count ≤350 | CD4 count >350 | Total |
|---|---|---|---|---|---|
| **UK** | **Full-time employment** | Number | 73 | 55 | 128 |
| | | Percentage | 57.0% | 43.0% | 100.0% |
| | **Part-time employment** | Number | 11 | 5 | 16 |
| | | Percentage | 68.8% | 31.3% | 100.0% |
| | **Unemployed** | Number | 35 | 22 | 57 |
| | | Percentage | 61.4% | 38.6% | 100% |
| | **In education or training** | Number | 5 | 2 | 7 |
| | | Percentage | 71.4% | 28.6% | 100% |
| | **Retired** | Number | 6 | 1 | 7 |
| | | Percentage | 85.7% | 14.3% | 100% |
| | **Self-employed** | Number | 0 | 1 | 1 |
| | | Percentage | 0.0% | 100% | 100% |
| | **UK Totals** | **Number** | **130** | **86** | **216** |
| | | **Percentage** | **60.2%** | **39.8%** | **100.0%** |
| **France** | **Employed** | Number | 27 | 20 | 47 |
| | | Percentage | 57.4% | 42.6% | 100.0% |
| | **Unemployed/ in education or training** | Number | 38 | 40 | 78 |
| | | Percentage | 48.7% | 51.3% | 100.0% |
| | **Retired** | Number | 2 | 0 | 2 |
| | | Percentage | 100.0 | 00.0 | 100.0% |
| | **Self-employed** | Number | 6 | 4 | 10 |
| | | Percentage | 60% | 40.0% | 100.0% |
| | **France Totals** | **Number** | **73** | **64** | **137** |
| | | **Percentage** | **53.3%** | **46.7%** | **100.0%** |

*3.2.7 Most likely transmission route*

The percentage of late diagnosis varies by transmission group in both countries. In line with the literature, the data show that men who have sex with men had the lowest proportion of late diagnoses compared to all of the other transmission groups. However, the percentage of men who have sex with men diagnosed late in the UK is higher than in France (50% versus 42.9%) which suggest that public health messages about the benefits of early testing aimed at this group may be more successful than the UK. Similarly, the percentage of heterosexual patients diagnosed late was also much higher in the UK (64.4% versus 52.9%) although the reasons for this are not immediately apparent. Differences in early and late diagnoses in both these groups are statistically significant in both sets of data although information about likely transmission is missing in the records of 4 UK patients and 1 French one.

**Table 9: Likely transmission route for patients with CD4 ≤350 versus CD4 >350**

| | | | CD4 count ≤350 | CD4 count >350 | Total |
|---|---|---|---|---|---|
| **UK** | **Men who have sex with men** | Number | 44 | 44 | 88 |
| | | Percentage | 50.0% | 50.0% | 100.0% |
| | **Intravenous drug users** | Number | 4 | 1 | 5 |
| | | Percentage | 80.0% | 20.0% | 100.0% |
| | **Heterosexual** | Number | 87 | 48 | 135 |
| | | Percentage | 64.4% | 35.6% | 100% |
| | **Other** | Number | 7 | 1 | 8 |
| | | Percentage | 87.5% | 12.5% | 100% |
| | **UK Totals** | **Number** | **142** | **94** | **236** |
| | | **Percentage** | **60.2%** | **39.8%** | **100.0%** |
| **France** | **Men who have sex with men** | Number | 15 | 20 | 35 |
| | | Percentage | 42.9% | 57.1% | 100% |
| | **Intravenous drug users** | Number | 0 | 1 | 1 |
| | | Percentage | 0.00 | 100.0% | 100% |
| | **Heterosexual** | Number | 63 | 56 | 119 |
| | | Percentage | 52.9% | 47.1% | 100% |
| | **Other** | Number | 4 | 6 | 10 |
| | | Percentage | 40.0% | 60.0% | 100% |
| | **France Totals** | **Number** | **82** | **83** | **165** |
| | | **Percentage** | **49.7%** | **50.3%** | **100.0%** |

*3.2.8 Place of HIV diagnosis (UK only)*

Clinical data on the place of the first positive HIV test were available in the clinical data for UK patients but not for the French patients. Four options for the circumstances or place of first test were identified in the UK coding scheme. The most common place of testing was the sexual health (genitourinary medicine) clinic, followed by tests done in hospital settings after admission due to an

acute illness. A smaller number also took place in the context of ante-natal screening, although the numbers of post-gravid women in the sample was very small. The figures show the pre-eminence of sexual health clinics in the testing and diagnosis of HIV in the UK although it is notable that so few cases were diagnosed in primary care settings such as GP surgeries. The full data are reported in the table below. The chi-squared value for this table is high (26.22) and statistically significant ($p<0.001$). The majority of patients tested following admission to hospital with an acute illness had low CD4 counts (89.1%) and were therefore diagnosed only after health problems had become apparent. Further information about comorbidity is contained in the next section, but it is worrying to note that more than half the women identified as HIV positive during ante-natal screening, were diagnosed with a CD4 count of 350 or less.

**Table 10: Place of first positive HIV test of patients with CD4 ≤350 versus CD4 >350 in the UK**

| | | CD4 count ≤350 | CD4 count >350 | Total |
|---|---|---|---|---|
| **Sexual health clinic** | Number | 61 | 62 | 123 |
| | Percentage | 49.6% | 50.4% | 100.0% |
| **Hospital admission due to illness** | Number | 49 | 6 | 55 |
| | Percentage | 89.1% | 10.9% | 100.0% |
| **Antenatal screening** | Number | 8 | 6 | 14 |
| | Percentage | 57.1% | 42.9% | 100% |
| **Other** | Number | 21 | 20 | 41 |
| | Percentage | 51.2% | 48.8% | 100% |
| **Total** | **Number** | **139** | **94** | **233** |
| | **Percentage** | **59.7%** | **40.3%** | **100.0%** |

*3.2.9 Co-morbidities at the time of HIV diagnosis*

Whilst deaths from opportunistic infections have declined with newer antiretroviral therapies, mortality from other AIDS defining conditions and non-HIV related conditions are likely to be higher in those who already have comorbidities at the point of diagnosis (Bhaskaran et al., 2008) so the impact of comorbidity cannot be underestimated. Data were therefore collected on co-morbidities at the time of HIV diagnosis in both countries. Data were missing for 3 UK patients and 10 French patients and in some cases, information about the particular comorbidity was somewhat vague e.g. 'respiratory' rather than a specific clinical diagnosis.

The overwhelming majority of people diagnosed late with HIV in the UK (119 individuals or 75.8%) were reported to have significant health problems at the time of their diagnoses in comparison to those diagnosed early. Of these, 63 already had an AIDS defining illness such as tuberculosis, pneumocystis carinii pneumonia, cytomegalovirus, Kaposi's sarcoma or AIDS wasting syndrome, defined as the involuntary loss of >10% body weight along with fever not associated with an opportunistic infection or cancer, and either chronic diarrhoea or fatigue. Those diagnosed late in France were also more likely to have AIDS defining co-morbidities, although the actual number was only slightly lower (47 individuals or 54.0% versus 40 or 46.0%) than those who did not which was not statistically significant.

**Table 11: Co-morbidities in those diagnosed with CD4 ≤350 versus CD4 >350**

| | Co-morbidity | Frequency | CD4 count ≤350 | CD4 count >350 | Total |
|---|---|---|---|---|---|
| **UK** | **Absent** | Number | 47 | 65 | 112 |
| | | Percentage | 42.0% | 58.0% | 100% |
| | **Present** | Number | 119 | 38 | 157 |
| | | Percentage | 75.8% | 24.2% | 100% |
| **France** | **Absent** | Number | 33 | 40 | 73 |
| | | Percentage | 45.2% | 54.8% | 100.0% |
| | **Present** | Number | 47 | 40 | 87 |
| | | Percentage | 54.0% | 46.0% | 100.0% |

### 3.3 Summary of findings and statistical significance of the clinical data

France has the highest HIV positive population in the EU (approximately 160,000) and a higher prevalence rate than the UK at 0.4 versus 0.3 (http://www.avert.org/european-hiv-aids-statistics.htm accessed 26/22/14). However, in comparison to Kent and Medway, a general picture emerges of a health system in Picardie (Amiens and Creil) which has been more successful in encouraging women, and those born outside the country to present for HIV testing earlier than their counterparts in the UK. Similarly, those diagnosed late with HIV in the UK region of Kent and Medway are more likely to have HIV related co-morbidities at the time of their diagnoses in comparison to their counterparts in France. In some cases, the co-morbidities were severe enough to have warranted much earlier testing had their significance been recognised early enough. Many of these were actually AIDS defining illnesses such as pneumocystis carinii pneumonia, cytomegalovirus and Kaposi's sarcoma including at least one case of CMV retinopathy leading to blindness. It is difficult to extrapolate from either of these two relatively small samples whether this picture is representative of an entire health system or not, but it would appear that the greater emphasis placed on the role of primary care practitioners in promoting early testing and detection of HIV in France is beginning to pay dividends although much needs to be done on both sides of the English Channel to increase the uptake of early HIV testing. This would extend to all of the population groups represented in the sample in the UK, but with particular emphasis on women and older people of both sexes over the age of 50 as well as men who have sex with men and migrant populations. In France there are still improvements to be made in reaching those born outside the country as well as those other groups affected. Notwithstanding these broader comments, it is possible to conclude the following analysis of the clinical data in both countries:

- Late diagnosis of HIV infection continues to be a problem in both Kent and Medway and in Picardie (Amiens and Creil) although the French partners in the study demonstrate better outcomes in respect of many of the variables considered than their counterparts in the UK.
- No significant difference in the levels of late diagnoses were found between participating centres in either country, although there were differences in the levels of late diagnoses between France and the UK with the French centres generally reporting better outcomes with regard to all of the variables reported. This led us to conclude that deficits are not unique to any particular centre and may instead, represent broader systemic or social

reasons why the uptake of HIV testing continues to be low amongst sexually active adults in both countries.

- It is clear that HIV is no respecter of age in either country with the oldest patients in the study being 81 in the UK and 71 in France. Whilst the mean age at diagnosis is slightly lower in France than the UK, older patients were more likely to be diagnosed late in both countries. This difference is statistically significant, and infers that more needs to be done to raise awareness about HIV and the benefits of early testing in both older adults and those who care for them. HIV should also be considered a potential cause of any un-attributable health problems, and certainly when indicators that an HIV/AIDS defining illnesses may be present irrespective of age, sex, or presumed sexual orientation.
- Just over a third of the combined UK/French sample in the study were women. This is consistent with commonly cited ratios of HIV infection in men and women internationally. However, women were more likely to be diagnosed later with HIV than men (53.3% of late diagnoses in France and 67.9% in the UK) although this difference was not statistically significant. This is at odds with assumptions that women are more adept at accessing health services for their own and other family members' health needs, and routine HIV screening in pregnancy.
- The samples on both sides of the English Channel were ethnically diverse, with 44% of the UK sample being non-white British and 51.5% of the French sample being born outside the country. Late diagnosis was more common in these minority groups in both countries. The differences are marginally statistically significant. This may be due to the number of migrants coming from areas of the world with a higher prevalence of HIV (such as southern and sub-Saharan Africa), but it could also, potentially be due to disparities in the provision of health advice and healthcare to these groups or indeed, cultural and political concerns about being diagnosed with HIV as will become apparent in the discussion of qualitative data.
- Four main transmission groups were distinguished on both sides of the English Channel. It is clear that those most at risk of HIV infection are sexually active heterosexuals, together with men who have sex with men. The number of those in the injecting drug user and 'other' categories were very small indeed in comparison to these two main groups. However, the profile of the transmission groups varies markedly by country of birth with men who have sex with men being more numerous amongst 'home-born' patients than those born overseas who were more likely to have contracted the illness through heterosexual intercourse.

## 4.0 Findings from interview data

Several common themes quickly emerged from the qualitative data as to how early testing and diagnosis of HIV could be encouraged. It is first necessary however, to acknowledge the social and psychological strain of receiving a positive HIV diagnosis and this came out particularly strongly in the French interview data which, using an analogy from Goffman's (1963) early work on stigma showed how little things have really changed for those affected by the virus, several French (and English patients) too saying things like:

*"Unfortunately, when you find out you've got it, you feel ashamed to begin with."*

*"It's the psychological impact that if I meet someone, will they accept it? How will I tell them? How do I do it? Yeah… That's the most difficult thing."*

*"I think it would be taken badly."*

According to Goffman (1963), it is not the attribute or condition alone which poses the problem, but the social relationships that are affected by it, changed by it, and sometimes, threatened by it. We know that social relationships between the HIV positive person and those not familiar with or otherwise unaffected by the illness can be affected deleteriously. This may lead to maladaptive behaviours such as seeking isolation or to actively control information about the illness which may leave others unaware of what is happening and confused by such responses in order not to become, as they see it in Goffman's words, 'discredited' persons in the eyes of others (Goffman, 1963; 1968). Goffman said in relation to stigma that, *'The problem is no longer so much knowing how to handle the tension that the social relationships create, as knowing how to manipulate the information about a failure: to expose it or not; to say it or not; to pretend or not; to lie or not; and, in each case, to whom, how, where and when'* (Goffman, 1963: 57). This is amply demonstrated in the following excerpts from French patient interviews:

*"I'm not really interested in the outside world. In fact, I avoid going out because I know that my friends are the ones that will spread the rumours."*

*I don't want to share that with my family, so I've created a bubble, I think I had the strength for that. There's actually me and what I've been since this disease and I only show me and not the part with the disease."*

*"I struggle with the embarrassment, I would say it's in terms of treatment, since when there are parties or things like that, you are taking a treatment, so of course I hide myself for that. And yeah, I manage to live while hiding it."*

*"Before I didn't want the news to spread, because if I opened up like that, I didn't know where it would go because carrying HIV, I lived in a student community, if people knew it would be a disaster."*

*"With my children yes we talk about it, and my partner, but not with everyone; and also a brother. But I don't want to let everyone know because it might make people scared if they know that."*

It is to their credit then, that so many patients diagnosed with HIV agreed to take part in the study and this section is unashamedly long so that as many voices as possible can be heard.

### 4.1 Patient satisfaction with sexual health services

Patients were extremely positive about the care received from specialist sexual health staff in both the UK and France. In the UK, this ranged from the point of first referral, through the testing, diagnostic and treatment phases. No negative feedback was received in relation to single members of staff or the UK clinics as a whole. On the contrary, several individuals were named on more than one occasion as offering exceptionally high standards of care and going beyond the remit of the professional responsibility to provide excellent care. One patient for instance said:

*"They assisted me...beyond probably their remit…The fact is that there is always someone I can call. I mean [name of clinician] has given me her number and has said you can call me at any time. And she has even replied back out of hours."*

Patients felt that their needs were attended to in these settings and that they were listened to and cared about as individuals. They felt that they received high levels of emotional and psychological as well as medical care from their clinicians, another patient saying of some of their carers:

*"[Name] and [name] were fantastic. Absolutely fantastic, I have to say. Great support… [Name] has become a friend really to be honest."*

A high degree of person-centredness with a commensurate level of emotional, social and psychological support was highly appreciated by patients at the GUM clinics, all of whom seemed to have developed strong, trusting, long-term professional relationships with their clinicians. There is no doubt that frequency of visits and continuity of care are important factors, in some cases, making a very desolate situation at the point of diagnosis more bearable in the longer term:

*"[Names] are just wonderful. They are. I think had it not been for them it would have been a whole different situation and it would have been just horrible. They were so supportive right from the very start."*

Similar levels of satisfaction were expressed by French respondents who particularly valued the input of their medical and nursing teams at the point of diagnosis when it was hard to discuss issues more fully with others. It was clear in this respect that they played an essential support role at this difficult time, some patients saying in respect of being able to discuss their fears and concerns:

*"There is only the team"*

*"With the professionals, I've talked about it more easily"*

Many UK patients expressed regret that they could not receive all of their health and medical care from these services rather than having other aspects of their health managed by their GPs. It was generally felt that there was little which could be improved in the sexual health clinics, other than making access to these easier and less stigmatising. It was notable in relation to this that older and in particular, older female patients found these visits more stigmatising, especially when they might be seen in waiting rooms etc. by people they knew.

### 4.2 Patient satisfaction with GP services

Patients in both countries were on the whole, quite critical of the care received by GPs in the time leading up to their diagnosis and in many cases afterwards. Many felt that their needs were not

listened to and that GPs did not view them holistically or seek to know them better. Most felt that the GPs they came into contact with knew very little at all about HIV or the needs of those who might be HIV positive, one patient saying:

*"I don't think their [GPs] knowledge of HIV and the way it's transmitted, and the symptoms, and how also how they deal with someone when they've contracted it is particularly good at this point in time."*

In some cases, patients (both French and English) felt that the knowledge showed by their GPs was little better than that of a lay person, and many patients gave examples of occasions when signs which should have indicated that an HIV test might be necessary were not picked up by their GP as the following two quotations demonstrate:

*"[I'd been to the doctor] a few times. They just thought it was a throat infection and bit of bad flu. They didn't even test for HIV or anything. It didn't cross their mind. I had thrush in the mouth, I was being sick…I couldn't stomach food, I couldn't even look at it."*

*"There are probably five or six main symptoms [for HIV] that as soon as the GP sees them, they should make that suggestion or they should send them for a test and they can pick it up so much quicker."*

Sadly, even once diagnosed, some patients felt that their GPs lacked sufficient interest to address these knowledge deficits or find out more about the condition they were now treating the patient for:

*"I think that GPs need to understand a bit more about it because there is lots of stigma around it and even the GPs aren't too fussed to understand much about it all."*

The stigma and embarrassment associated with an HIV test or positive diagnoses often made for difficult encounters with a patient's GP even after the initial subject of an HIV test had been broached, as illustrated by the following excerpt from the data:

*"My GP who I had been seeing all the time…he's a very nice guy… but he seemed like… quite shy. And even when I got the call to go back to the GP I sat down, and he was sat there, and asked 'how are you?' 'As good as I can be' [I replied] and he just sat there looking at me. And I said 'so was the test positive?' and he said 'Yes'. I mean, and this is not being derogatory of people with cancer, but if someone had cancer, would he sit there in exactly the same way? I don't think he would."*

There were many examples in the UK data of GPs making assumptions about a person's HIV risk based on age, appearance or presumptions about a person's sexuality. Interestingly, this appeared to put older heterosexuals and particularly women at risk of not having their concerns about HIV infection acted upon. Several patients recounted discussing concerns that their symptoms might be HIV related only to be told that it was highly unlikely given that they were in a stable heterosexual relationship and did not belong to any 'at risk groups'. The notion that HIV was a condition affecting gay men and certain ethnic minority groups was still prevalent amongst many GPs according to some patients. These attitudes and the stereotypes which underpin them must be addressed as a matter of urgency as in some cases patients felt demeaned or ridiculed by their GPs for asking about having an HIV test.

This situation was equally represented in the French arm of the study which suggested that patients might be met with a certain level of indifference on the part of their GPs. As in the UK, few GPs had experience of caring for someone with HIV, and this discouraged them from seeking appropriate training or professional development to prepare them to provide optimal care for such patients. Consequently, in spite of official rhetoric that they are the primary providers of HIV prevention and diagnostic services, few of the French GPs questioned routinely offered an HIV test to their patients except in a very small number of cases. Interestingly, these included pre-marital testing, ante-natal testing, occasionally during the course of a gynaecological examination indicating that a sexually transmitted disease may be apparent, or during screening for sexually transmitted infections. Some French GPs seemed reluctant however, to ask male patients about their sexual histories or preferences, even when they had suspicions that a male patient might be at increased risk of HIV as the following demonstrates:

*"I think that there are patients, I don't imagine that they have risky behaviour, because you're not necessarily going to consider during the 10 minutes from time to time that you see them, that they may have sexually, or even drug-related, risk behaviours. There are some people where you have your doubts. But I don't know if I would be able to say to somebody, in short, to bring up [the question of] homosexuality for example with a man, and propose he be tested only on the basis of a suspicion. I think that I would be able to do it. To say to somebody, 'are you homosexual?' and in this case you should [be tested]".*

It seems therefore, that in both countries, it is often the patient who has to suggest the need for an HIV test due to GP embarrassment. This embarrassment seems to persist however, even in the presence of a positive test, as the following quotation from a French GP demonstrates:

*"You're never very comfortable. Of necessity and taking your time, the patient is informed during their appointment…. I beat about the bush a bit at the beginning, I'm not going to say to him, there you go, here's your result".*

Likewise, some examples were given of occasions on which GPs (and other healthcare professionals) in the UK failed to spot obvious indications that the patient might be immunocompromised and at times, the more marked signs that they were experiencing a seroconversion illness. Many more reported receiving numerous sequential misdiagnoses before an HIV test was finally suggested, and in some cases, patients had endured prolonged periods of treatment (including hospitalisation) for conditions which they were subsequently found not to have, as the following long but detailed quote from a 54 year old heterosexual male clearly demonstrates:

*"I had been very ill for about nine months. I was getting diarrhoea, weight loss, candidiasis in the mouth and what I later found out was molluscum on my face. I was backwards and forwards to my GP for nine months, I saw two gastroenterologists, I lost 4 stone, could barely walk and no one really seemed to understand what it was. When you consider the amount of professionals I actually saw. I had an endoscopy, I had a colonoscopy twice, and to not even get it [i.e. the diagnosis] from that was unbelievable. I was sat down in front of about ten or twelve people, professionals, and not one of them come up with it… I wouldn't want anyone going through my experience of all those months of going downhill and down, your family in tears, because they think you're dying."*

In at least one other case, a patient suggested that their GP disregarded a letter provided to him by an occupational health physician recommending that he investigate a patient's HIV status and drawing attention to the fact that he might have been misdiagnosed with a stomach bug for which the GP had recommended yoghurt, when his own suspicions were that it might have been pneumocystis carinii pneumonia:

*''And the Occupational Health guy when I went to see him took one look at me and said I'll tell you what's wrong with you. You've got pneumonia'…. So he phoned my GP up and said you must see this guy quickly. And I went to see my GP on the Monday… by which time I couldn't actually get there under my own steam so I got a taxi there, and again he said 'you've just got a stomach infection. I've told you once".*

In this case, the patient was known by the GP to be a homosexual, but assumptions that he was not, or had not recently been sexually active because of his age had led him to conclude that it could not be an HIV related condition. The patient subsequently became extremely unwell but requests by his family and friends to review him urgently were ignored with the GP insisting that his original diagnosis was correct and the patient made to feel like a hypochondriac. As a result, this previously healthy man was admitted to an acute hospital unable to walk or stand without assistance by ambulance within 24 hours, and was subsequently transferred to a specialist unit in London where he remained for several weeks in a critically ill condition.

This is clearly an extreme case, but similar instances were recounted by patients who felt that they had to work hard to convince their GPs that they might need an HIV test. For many, HIV simply did not seem to be *'on the radar'* of their GP and many only considered it as a possibility as a last resort. Patients often commented however, that GPs were quick to suggest that a diabetes or cholesterol test might be beneficial without any clinical indication for such a test being present. In a small number of cases, patients felt that requests for an HIV test were declined or evaded because of a perceived lack of time or fears about the emotional response to a positive result in a necessarily brief GP consultation. This is particularly worrying however, where patients are reluctant to attend a GUM clinic for testing as one older heterosexual women accompanied first time by her daughter suggested:

*'' My daughter said to me… 'Oh my God. I've got to sit there'… because there was a sign saying GUM [sexual health clinic] on the desk… I just said, just because you are sitting there, it doesn't mean to say you are not going to go there, or go upstairs or something. But it is. The label is bigger than the word itself''.*

Observations made by UK patients about GP services seem to accord with the observations made by the five UK GPs interviewed in the British arm of the study. These individuals seem to be in the vanguard of the profession and were regarded as HIV specialists in their practices for the most part, but their critique of fellow GPs reluctance to discuss issues of a sensitive or sexual nature for fear of opening a *'Pandora's box'* of concerns within a ten minute consultation seem to accord with the observations of many patients. They were critical too at times about the lack of knowledge demonstrated by fellow GPs in this area, and of outdated assumptions about those likely to be at risk of HIV based on assumptions regarding the age, marital status or sexuality of their patients or indeed, the communities they loved and worked in. These respondents also felt that some GPs are fearful of offending patients by asking difficult though necessary questions at times and said nothing

which would contradict the views and experiences reported by several patients in the study. The same was equally true in France however, one French GP acknowledging:

*"With young people it is not too much of a taboo [but] with older people, perhaps a little more. With 45-year olds, people in their fifties and sixties, a whole generation…. which in short did not use condoms in their sex lives, [I am] always a little more reticent when speaking about this kind of thing".*

Interviews conducted with French GPs show that taboos about discussing sex and sexuality frequently stops them from establishing a dialogue with their patients as they feel unable to converse about emotional, relational and sexual issues with their patients, particularly in older patients. French GPs found it equally difficult, in spite of their espoused lead role in HIV prevention, diagnosis and care, to provide help and information about HIV prevention. Some also felt inadequate at the time of diagnosis, a situation with which many were unfamiliar. Often, they wanted to be able to offer reassurance about long-term survivorship and the chronic, rather than fatal nature of the illness, but felt badly equipped to do so. Consequently, the French report shows that these GPs in particular are less likely to follow-up their newly diagnosed HIV patients in the aftermath of this event which is sad given that the interface between acute, specialist, and community-based medicine is still far from seamless in France, as in the UK.

**4.3 Patient satisfaction with acute hospital services**

UK patients reported having mixed experiences of acute hospital care. In some cases, the care described was excellent, particularly in some of the specialist centres:

*"I was extraordinarily impressed by the treatment from the NHS. Most particularly the standard of care at consultant level and in particular up in London. Flawless really".*

They were often the place in which patients were initially diagnosed, although not always quickly, and in some cases, patients might have received long periods of treatment without having the actual cause of their illness recognised as the following demonstrate:

*"I know you have to ask if people about being tested… but surely it's better to just ask and get it done sooner rather than later. I mean if they had done that…months earlier…I would have been nine months of not being the way I was which would have saved not just heartache for myself, but it would have saved a lot in terms of resources over that time."*

*"For about two years before I thought I had irritable bowel syndrome and you know the hospital did as well… it went on for ages and ages and then the penny dropped what it was… I even went through an operation to have a lump removed, and still nothing was detected. And nothing was said, nothing was even mentioned, nothing was even suggested. I reckon that process probably went on, well getting on for a good nine months probably."*

In line with patients' experiences with GPs, speedy diagnosis sometimes seemed to depend on the attending physician's perception of the patient's risk status. One homosexual patient was surprised that a hospital consultant had not considered HIV as a possibility after having had several opportunistic infections only to be told when saying to his consultant that he was in a vulnerable group, *'well my radar is obviously not very good any more'.*

In at least one other case, an HIV test was only finally carried out as a result of the patient's continued and firm insistence that she would like a test to rule out HIV as a possible cause of serious long term health problems which sadly, proved instead to be the case. Once diagnosed and treated appropriately, she made a swift recovery after many months of intermittent hospital admissions and costly investigative procedures for a sequence of debilitating illnesses which kept her bed-bound at times.

*''Interviewer: 'so you suggested having an HIV test yourself?' Patient: 'Yes because all the other checks that they were doing for me in the hospital were really good. My heart was perfect… my lungs was [too] thank God. And I couldn't believe it. Sixty-three isn't that old… and I couldn't… nobody could think what else could it be, and just in my head, I thought well let's eliminate that [HIV]. But it didn't. It came [back] positive".*

The problem of synecdoche seemed to be apparent in many such cases, and consideration of the patient's immune status was often missed amidst the search for more 'obvious' explanations for the patient's condition. Many patients could not understand why HIV status was not routinely assessed on admission to hospital as part of the gamut of tests and procedures undertaken. One felt that it should be no less routine than swabbing for MRSA or urinalysis at the point of entry into the system, a sentiment voiced in different ways by many others.

In at least one case, unhelpful and inaccurate information was given by a nurse to a patient's relative (who herself suffers from obsessive compulsive disorder) about 'contagion' risk which resulted in her refusing the patient access to her grandchildren which persists to this day. The distress caused by this healthcare professional's inappropriate actions was more than apparent during the interview, as were her feelings of anger and betrayal by those who should have had a duty of care towards her.

Other patients felt that the care they had received in acute settings was good once their status was known with those referred to HIV specialist centres in London voicing the highest opinion of acute care services. At least one patient with experience of both had been told by his London Consultant that the treatment he had been prescribed elsewhere was 'archaic' although this is an isolated case and may be anecdotal. What is clear from the data is that patients' experiences prior to diagnoses were many and varied. They were far more heterogenous than might be anticipated by the relatively small number of categories used to elicit their information in the quantitative survey of patient data and each patient experience was rich in anecdote and experience with some particularly good examples of a lack of person-centredness which may be due to a lack of time or unwillingness to listen to a patient's concerns, particularly but not uniquely in the GP practice setting.

**4.4 Access to information about HIV**

Many patients acknowledged having only limited knowledge about HIV risk, transmission, its diagnosis, treatment, and long-term outcomes prior to diagnosis. Men who had sex with men appeared to have better knowledge about its transmission, diagnosis and treatment, often from their own or a friend's experience, or the many health promotion and education messages portrayed in the gay media or in places where they regularly associated (pubs, clubs, saunas etc.) This was by no means complete however, some respondents for instance failing to recognise the risks involved in oral sex and attributing their infection to this activity as the following demonstrates:

*"I am certainly not engaging in anal sex in a flipping layby you know. People do, but it would probably be oral sex and swallowing sperm really. That is it. That is probably where it came from. I can think of nothing else. And even then I would have had to be quite unlucky… but clearly I was."*

At least one bisexual male in the UK arm of the study felt that men who have sex with men are *'more switched on'* to the benefits of early testing and had easier access through the 'gay scene' and media to sources of information and support, although some older men who have sex with men would not concur with this view, and voiced concerns that older gay men are as unlikely as heterosexual men to access all of this information given the ageism that some felt to be present in the gay scene itself. They like others, made extensive use of online sources of information and support however, unlike some other groups prior to diagnosis.

Heterosexual respondents also concurred that there was probably greater exposure to targeted health promotion and education materials in the gay community, as did the bisexual respondents. This group in particular felt very isolated from mainstream HIV support services which they regarded as being predominantly targeted towards men who have sex with men and people of afro-Caribbean origin, especially in the Medway area in England, where the work of the Health Action Charity Organisation (HACO) in particular is well publicised but only offers support to ethnic minority groups. The policy of other charities such as Terrence Higgins Trust in only offering postal HIV self-test kits to those deemed 'high risk' in the UK was also resented by some who were not within their target service user groups. Other services, such as those offered in Kent seemed to be more generic with the needs of HIV positive service users being less visible on their websites which appeared to be aimed at providing financial and employment help/support rather than emotional or psychosocial support, or indeed, health education to people affected by HIV.

Clearly, many of the men (of all sexual orientations) interviewed for the study had been shocked and surprised to find themselves diagnosed with HIV although it is clear that in line with the literature, men who have sex with men are more likely to be diagnosed early. Women (particularly older white women) were more likely to present later for testing, and this appears to be borne out in both the qualitative interviews and quantitative survey data in this study. Unlike most of the men interviewed, the majority of women interviewed had no idea that they might have been exposed to HIV and attributed their seropositive status to infidelity on the part of their partners, including one very religious black African woman who had only ever had one sexual partner (her husband) prior to her diagnosis who had died of an unspecified illness in Africa some years before.

Whilst internet use amongst young and predominantly homosexual males was high, the vast majority of respondents reported that most of their knowledge about HIV prior to their diagnosis came from the popular media, predominantly newspapers and the television, but these were widely regarded as unreliable sources of information in the light of their subsequent experiences although some felt that the coverage of 'celebrity' deaths or infections with HIV might serve to increase others' decisions to get tested. One current storyline in a popular UK television programme about an older woman infected with HIV by an unfaithful partner was mentioned by several respondents as being realistic and thought provoking. It transpired that the storyline had been introduced into the programme as a result of one of the older female respondents in the study writing to the television channel concerned to complain that many prominent HIV storylines were predicated on the experiences of younger and predominantly male characters, usually men who have sex with men.

Almost none of the respondents could recall seeing information about HIV/AIDS or HIV testing services displayed prominently in their GP surgeries, although they had all seen such materials in the GUM clinic or other acute hospital settings. Some concluded from this that HIV testing was not regarded as a core activity of primary healthcare professionals in the GP settings although most thought it should be and if true, this is particularly regrettable for those who feel uncomfortable accessing the more traditional GUM services for fear of recognition or stigma.

**4.5 Patients' understanding and perceptions of HIV and HIV risk**

All of the patients interviewed intimated that their understanding of the illness was better than when first diagnosed, and that their perception of HIV as a chronic rather than a terminal or life threatening condition had changed as a result of their diagnosis and treatment, largely thanks to those caring for them in the HIV units. Some, particularly those from black African and Caribbean backgrounds were still wary of divulging their diagnosis to others given the poor understanding of others about the condition and possible repercussions of this. They were not unique in this however, and many others could cite examples where others' knowledge was at best rudimentary and at other times completely erroneous including, but not restricted to some healthcare professionals. Once again, men who have sex with men were more likely to have a better understanding of the condition either as a result of others' experiences, or the internet and other health literature, although the knowledge of at least one older gay man was limited in some respects. Most patients did not perceive themselves to be at risk however, unless they felt unwell, one French patient saying, *'I had no idea at all that I was carrying HIV. I had no sign showing me that I was carrying the disease.'*

**4.6 Patient's perceptions of HIV as a condition of relevance to them prior to diagnosis**

Interestingly although perhaps not surprisingly, nearly all of the patients interviewed had been shocked and surprised to learn that their HIV test had proven positive – even amongst those in so called high risk groups. For some of the heterosexual women, this is not surprising, but even amongst younger men who have sex with men there was a sense of invulnerability and an assumption that the virus was something which affected other people. Evidence for the presence of cognitive dissonance is clear within the study population, with many actively engaged in risky behaviours refusing to believe that they might become infected. This included at least one highly educated, young, erudite and well-informed gay male who regularly, until his diagnosis, visited gay saunas in London for the purpose of engaging in 'bareback' sex with other men.

Perceived health status was also an important determinant in deciding whether they might be at risk of diagnoses, it being for the most part, something that patients did not consider until or unless they became unwell or had other concerns about their health. In some circumstances however, patients who generally felt well were devastated to find that they were HIV positive, as the following quotations from French respondents demonstrate:

*"It's as I just said, I didn't have to, it wasn't during an examination or check-up that they found it. I did it voluntarily. I asked to be screened voluntarily. I didn't know why, I felt fine, I had ambitions. And then, it was the holidays and I told myself I should use the chance to have a check-up and there you go. The verdict came in."*

*"I had no idea at all that I was carrying HIV. I had no sign showing me that I was carrying the disease."*

### 4.7 Length of awareness prior to HIV testing that the patient might be HIV positive

The length of time that a patient suspected themselves to be HIV positive prior to seeking testing varied enormously and broad generalisations cannot be made about any particular group in relation to this. What we know from the literature, and seems borne out by our data, is that men who have sex with men are more likely to present for testing earlier, and hence have a shorter 'lead in' time to diagnosis. It is not entirely clear on the basis of so small a sample however, whether this is because they are more likely to have regular HIV tests as recommended for sexually active men in this client group, or because they or their physicians are more attuned to the clinical signs of possible HIV infection. In some cases, this seems definitely not to have been the case, and diagnosis was as a result of surreptitious screening or hospitalisation for other causes (such as non-HIV sexually transmitted diseases, hepatitis etc.), but in some cases, even very experienced and knowledgeable individuals still did not anticipate a positive result to such a test. Moreover, as we have seen, others had to overcome significant barriers to get their GPs to acknowledge the need for such a test although most were more likely to access this through sexual health clinics in the UK or voluntary agencies in both countries. Other patients, particularly those diagnosed as a result of routine screening in antenatal clinics or as a result of negative investigations into other causes of their ill health had little time to prepare themselves for either the test or its outcome.

### 4.8 Likely cause of transmission

Unsurprisingly, respondents tended to attribute their HIV infection to the most likely known cause for transmission, predominantly unprotected sexual intercourse or other sexual activity, intravenous drug use, or in one case, a potentially infected blood transfusion received by a black African female respondent in her home country, although her first husband and only sexual partner until that point had also died of an unspecified wasting disease back in Africa prior to her coming to the UK. All of the patients understood the risks of unprotected sexual intercourse and intravenous drug use, some wondered whether barrier protection methods had failed them in the past, but many of the heterosexual men and women had not thought that they faced any significant risk by engaging in unprotected sex with an established partner of the opposite sex or another sexual partner they presumed to be exclusively heterosexual.

### 4.9 Decisions leading to an HIV test being taken

Unsurprisingly, apart from routine antenatal screening, generalised illness, malaise or specific symptoms indicative of an HIV infection or some other illness were the main reasons for patients seeking an HIV test. Less common reasons were exposure to a known risk such as intravenous drug use or the diagnosis of a current or previous partner with HIV. Relatively few patients subjected themselves to regular testing even when in an at risk group or engaging in risky behaviours, and it would seem that even when the risks are known, positive symptomatology is the main reason for patients seeking a test of their own volition. Where patients were tested at the suggestion of a medical practitioner, this was primarily within the context of other medical tests. One French respondent for example said:

*"She [the doctor] suggested that I give a blood sample at a laboratory near my home and then based on that, receiving the results and then meeting with my doctor again for various explanations, what I would have to do, and so one thing led to another".*

Frequently within the French context, these tests were correctly taken as a result of patients exhibiting symptoms indicative of possible HIV infection as suggested by the following:

*“[I had] a tubertest, a tuberculosis test I think. I came back a few days after to see if there had been a reaction. In the end, they realised that there had been a reaction. They thought an HIV test should be done. They did a test and it came back positive. That's how I found out."*

*"It was a blood sample with other tests on my venereal health done by a general practitioner. So I asked him for HIV as well."*

Tests in both countries were sometimes initiated by patients and at other times, by healthcare staff, but it is difficult to ascertain any definitive pattern which would indicate how the uptake of early screening could be increased, other than better education and training for healthcare practitioners (GPs being a priority is would seem), or generic health promotion for all members of the general public.

Where patients had time to reflect and make the decision for themselves, anxiety about the impact of a positive result, fear of stigma, worries about employment, relationship issues including how to break the news to a partner, friends or other family members, financial, and insurance concerns were prevalent in causing them to delay seeking an immediate test. It is also interesting to note that many patients cited anxiety about their medical records not remaining confidential, especially in UK GP practices or small communities where patients were likely to know or see clinical staff socially, or where other members of the family might also be registered. These concerns were also voiced by most of the UK GP respondents who also identified poor soundproofing of waiting rooms and reception areas in small practices, and the possibility of clinic staff knowing patients socially as possible causes of embarrassment. GP clinics were not alone in this however, some patients reporting that they preferred to attend sexual health clinics in towns many miles distant from their home, or even in London rather than those in their own towns or cities for fear of being seen entering or leaving the premises.

Family members’ opinions did not seem to feature highly in a patient’s decision to get tested, although testing had been suggested by close friends in some circumstances. As indicated already, few patients generally anticipate a positive result, but a small number reported feeling relieved as it made sense of signs or symptoms they had been experiencing for a long time:

*“As soon as I got that medication it was miraculous… and I thank God for [name of clinician] and for them [indicating to the nurses and doctors] out there… they have stopped one of my medications because they said, the viral one, I don’t need that now, because my counts are really good… but the other ones I will be on for life…. but who knows what is going to come through tomorrow”.*

### 4.10 Reasons for continued poor uptake of early testing

Most patients and some healthcare professionals interviewed were surprised that routine testing and screening for HIV is not more common. Many said that misunderstandings about HIV and the stigma associated with it will only be improved when HIV testing becomes as routine as having a cholesterol test. One UK patient said that early testing would only be achieved by, ‘*making it normalised and accessible. So you don’t have to go to a certain place which is, may have a stigma, it*

*could be available anywhere. And you can get access to support at other places other than a GUM clinic perhaps.'*

Whilst sexual health clinics in the UK were regarded as places where excellent HIV care was provided, many still felt the stigma attached to visiting the clinics and this might preclude people from visiting them for regular testing, particularly when they share reception areas or waiting rooms with other services as the following two quotes demonstrate:

*"I don't think it is still seen as a healthy thing to do. You must be going to a GUM [sexual health] clinic because you think you have caught something."*

*"I went to the main blood test section, phlebotomy, which is fine because everyone is there. No-one knows why you are there, do they? But then I obviously came straight here [GUM], which I thought was a little bit daunting. When you walk in and there're rows of people, you know."*

This view was also shared by UK healthcare professionals, particularly the GPs interviewed for the study in Kent and Medway. There is a strong view that HIV needs to be demystified and de-stigmatised, and that public health messages about the risk of HIV infection in non-typical groups be better understood by healthcare professionals and the lay public alike, some arguing that it should be possible to undertake an HIV test in a private booth in church or school halls, libraries or workplaces in much the same was as others might to go there to donate blood and have it seen in as positive a light as this.

**4.11 Reasons for continued poor uptake of early testing**

All of the older respondents, both patients and healthcare professionals could recall the graphic public health campaigns of the 1980s and 1990s in relation to HIV/AIDS and had vivid memories of these. Many remembered them as depressing and anxiety inducing:

*"I remember a TV campaign around about mid-80s. It was quite a hard hitting campaign on the television and it went by certain names which I don't think is very nice to talk about…But it was all, if you've got it, that's it. You're going to be dead within so many months or whatever, and I think that was the stigma with it."*

They felt that these had also contributed to HIV being seen as a 'gay disease' and felt that it was time for outdated ideas such as this to be challenged:

*"I think because it is a virus that can affect anybody, I don't think it matters. You haven't got to be a gay man. It's affecting straight ladies as well. Even post-50 [year old] people are getting infected so I think more people need to be aware of that it is not a stereotypical illness."*

Once again, many thought that health messages were reaching too narrow a population and needed to stress that anyone could become infected as the following two quotes demonstrate:

*"There is lots of adverts in gay magazines …but should they have those in heterosexual magazines? .. Because then it doesn't become a gay man's illness does it? It is everyone's problem."*

*“Another advert would be normal people. Not looking ill…And maybe the fact that you can’t tell by looking at someone. I mean it is a hidden disease, right? So you’ve got to be careful. No matter what really.”*

Data from the French arm of the study suggest that the four main reasons for continued late screening are a feeling of not being exposed to a risk; HIV remaining ‘invisible’ as a potential cause for concern in the general public, and indeed, some of those likely to be affected by it; stigma and finally, cultural limitations on the discussion of sexual risk and practices. Many of these chime with findings from the UK interview data, one French respondent saying, *‘as a married person, with no risky behaviour, I had no reason to worry’* – a comment which matches several UK patient and health professional comments which attribute marital status with a reduced risk of infection.

Others clearly also felt that they had been infected in spite of taking appropriate precautions, particularly prolonged condom use, although fewer respondents understood how the virus could be transmitted through other means such as unprotected oral sex as these two French respondents indicate:

*"I was with someone and we had said that we'd do the test to avoid having to use condoms. So I did the test straight away and it was then that I was very surprised at being HIV-positive."*

*"To be honest, I didn't suspect it at all. I was careful too, so to be honest it surprised me."*

Culture also undoubtedly also plays a part in continuing poor rates of HIV testing with many respondents from ethnic migrant groups in particular saying that it was taboo to discuss the use of condoms or HIV testing in their communities. This was particularly difficult for women from communities in which male hegemony and hierarchy were pre-eminent. The same was true in regard to communities where strict religious or moral mores were preserved. One French respondent of sub-Saharan origin said:

*"Back home, we don't talk about it much, but even protecting yourself is difficult, buying condoms is looked down on. If someone sees us buying condoms, it's not because I'm infected, but because you are going to sleep with someone."*

Another French respondent said:

*"If I had found out in Rwanda it would have been a disaster... in Rwanda I was in a position of responsibility. .. I was not anonymous. For me too, I know lots of people with HIV but it wasn't them who told me, sSo there is no anonymity, in Rwanda in any case."*

Hence, Thiaudière’s (2002) comment that ‘*HIV infection, as a chronic disease, requires the patient to continually adapt…. the disease requires them to deal with two sets of constraints: the medical institution and the private life’* (p71).

In the UK, respondents felt that any health promotion campaigns should accentuate the positive benefits of early HIV testing rather than the consequences of not doing so, and there was also concern about the sexual health of younger generations in the light of increasing STD rates and perceived increases in the sexualisation of children and adolescents’ relationships due to peer

pressure and social advertising. Many suggested that greater efforts should be made to increase health promotion and screening programmes for younger people at school:

*"I think with a lot of youngsters… they are very careless… I think they should go into schools [raising knowledge] from chlamydia to this to that [asking] Are you aware of what could happen?"*

**4.12 Observations from UK health professional interviews**

Without exception however, each of the five GPs interviewed in the UK highlighted areas of poor practice and a general lack of HIV awareness and training amongst the profession including at times, specific individuals in their own practices. One of the aims of the project was to identify poorly performing practices, but it is perhaps not surprising known or suspected 'poor performers' did not come forward for interview whether knowledgeable of this status or not. Those GPs who came forward were clearly at the vanguard of the profession and many said that they had come forward because they were concerned about current deficits in most if not all of the GP practices they were aware of. These respondents tended to have a negative view of their peers willingness and ability to confront problems with patients which should have altered them to the patient's sometimes advanced HIV status. Several intimated that HIV is simply *'not on the radar'* of their colleagues, an observation noted by many patients; either because they consider it to be primarily the remit of sexual health clinics, or are too constrained by other policy objectives to pay it much attention.

One of the UK GP respondents suggested that, *'GPs don't get paid to think about HIV as they are other chronic conditions such as diabetes and obesity'* and another suggested that financial remuneration for HIV screening and uptake would significantly increase their interest in the condition, but without it, this was unlikely to occur. Most also suggested that misunderstandings and confusion about the need for 'pre-test counselling' constrained GPs from raising the topic as they considered a maximum ten minute consultation too short to deal with such issues. Sadly however, in not raising the topic at all, many subsequently were felt not to refer patients in need of an HIV test to a sexual health clinic either and felt that it was better not to raise it as the patient would make their own decision in the end.

Recruitment of medical specialists from the acute hospitals was disappointingly low in the UK and there were none in the French arm of the study. However, the recruitment of 3 HIV specialist social workers, a specialist pharmacist, a clinical nurse specialist and a sexual health nurse helps to provide a better sense perhaps of the multi-professional management of HIV now that it is recognised as a chronic health problem rather than a terminal condition. Their views are surprisingly similar to those provided by the patients however. Healthcare professionals were selected for interview in the UK using a purposive sampling method – predominantly at the suggestion of consultant sin the sexual health or GUM clinics, but the unresponsiveness of many to the invitation to be interviewed may owe more to competing clinical pressures in these areas as research fatigue or ennui. Some who were interviewed (e.g. a gastroenterologist) did not regard the management of HIV patients as the fulcrum of their work and had a more site specific focus preferring instead to refer HIV patients back to the GUM specialists where these were unconnected to the task in hand and would refer HIV patients to a specialist HIV unit had they known their diagnosis in advance.

**4.13 Observations from French health professional interviews**

The interviews with 51 general practitioners in France elicited a rich source of information about their attitudes to HIV prevention and testing. In the main, they tended to recommend tests at

specific milestones in the patients' lives such as prior to marriage, during pregnancy and during clinical gynaecological examinations in addition to discussions about sexually transmitted disease or when patient's specifically requested a test. These requests were more common when a patient had a new sexual partner or wanted to stop using condoms where a relationship was considered to be stable – particularly in men who have sex with men and sub-Saharan African patients. They also tended to recommend a test where patients had returned from a visit to countries of high HIV prevalence where intercourse had occurred with local people. There was frustration with the reluctance of some patients to adhere to their recommendations however, particularly those perceived to be living 'chaotic' lives as the following demonstrate:

*"I offer a test, but with these patients [i.e. those with potentially HIV defining illnesses] it's very difficult to get them to do even a simple blood test".*

*"Sometimes it's somebody who will simply vanish… you might offer a test but a priori it won't be done because he leaves. So, it is true that itinerants, all these people who wander in no particular direction and whom you see like that on a one-off basis…. you realise that they have risky sexual behaviours, or they mess around with drugs or things like that. You'd really like to know a little more about it and sometimes you speak to them about it but, in any event, it doesn't make much difference".*

*"I have homosexual patients to whom I've said, where are you up to with your blood tests? When you speak about their sex life, it is a rather particular sex life. And I would say unfortunately, that they are using a little less protection than they used to. So it's easy to tell them to take a blood test''.*

A willingness on the part of GPs to recommend an HIV test at the patient's request was noted in some interviews, although the age of the patient does seem to be a defining factor as in the UK with regard to their discussing the need for a test as the following two quotations show:

*"Not here, there's really no problem, frankly. I have never been embarrassed to ask the question. Every time I ask them, it's me who brings it [the need for a test] up it if I can".*

*"With young people, there isn't too much of a problem, I approach it quite directly. With people more than 50 years of age, it's rare that I approach it spontaneously, in that case I'm more likely to respond to a question… the older the people are, the more difficult it is".*

However, few of the French GPs were involved in giving a positive result to patients and they sometimes expressed relief that they did not have to do this although some did not experience such doubts. Usually, this was because they had not had a seropositive patient so far as they knew.

*"It's very simple for me. I have never had a positive serology. So I've been very lucky, that's how it is. I have no HIV positive patients".*

*"Up until now, that hasn't happened to me. I haven't had a HIV positive result".*

On respondent even asked the interviewer, '*can you summarise for me what you [should] say to an HIV positive patient?*'

In spite of the apparent callousness of some, when the need to share a positive diagnosis arose, some found this quite difficult, and there was some experience of good practice as the following testify:

*"You just have to take your time, you don't tell them in two seconds flat. It takes a good three quarters of an hour to an hour, to go over everything".*

*"You can say to a HIV positive patient that he's got the virus but that he's not necessarily ill. So you try to reassure him, to tell him that if he's not ill…. [but] if he is ill, there are treatments which can be effective now and which offer a long period of survival, so you reassure them as far as possible".*

*"A young woman came to see me almost as an emergency because of a condom which had burst during congress with a known HIV positive individual. I immediately sent her to the hospital, and she received the classical treatment as there had been fewer than twenty-four hours since the incident. She had the whole gamut of treatments. She had all kinds of things to prevent her becoming HIV positive herself".*

In contrast to this happy outcome, some GPs found it difficult to reassure patients who did receive a positive HIV diagnosis, often because of the patient's fears and reactions to the diagnosis, or the charged emotional atmosphere that discussion of a positive test generates.

*"When we speak to them, telling them that HIV is no longer something to be scared of, because you don't die from it anymore, and you can have a good life with it. It's difficult for them to understand".*

In line with the small number of UK GPs interviewed, some French GPs thought that they did not have enough knowledge about HIV, and less still about its treatment, thus any effective strategy to improve the uptake of early HIV testing must involve the permanent development of technical knowledge and communication skills (Souville 2002) as demonstrated by the following:

*"Knowledge? No. I am not very comfortable. I am not well trained because I belong to the 1980's and we weren't highly trained. It's changed a lot, but there wasn't a great amount of teaching on the subject. And at the FMC level, on HIV infection, there's not much on offer".* [3]

*'When effectively you don't have any [HIV patients], you're a bit less up to date and less well informed about the latest techniques or treatments. Afterwards, it is enough to take part from time to time in refresher courses with FMC or to get a bit of information about the treatments by re-reading the literature or on particular Internet sites'.*

The majority of respondents made little or no comment about the follow-up of HIV positive patients after the screening and diagnosis giving, even though 'therapeutic follow-up' has been added to GPs screening, advice and guidance activities in France. In many cases, GPs do not expect to see the patients again after testing and/or giving the diagnoses, and in some cases, not even then as the following show:

*"I think that I had one [HIV positive patient], but in fact he 'short-circuited' me and went directly to the hospital to get himself treated".*

[3] Films Médicaux et Chirurgicaux i.e. Medical and Surgical Training Films

*“I will explain to them that the test is positive and that I will immediately send them to see a specialist at the hospital because it is not something which I will in any event manage myself”.*

*“I've had two or three of them recently and some of them you don't see afterwards because they are treated in hospital. When they've been diagnosed, they are not necessarily followed-up”.*

## 5.0 Methodological limitations

Cultural and legal requirements meant that data collected during the clinical review of patient notes in France were sometimes slightly different than those in the UK (for example, in relation to the omission of data on ethnicity), but these differences have to be acknowledged and not under the control of researchers in either country. Likewise, as in any retrospective review, there were many missing values in the data, but where possible, these have been taken into consideration when drawing conclusions from the data and there is a strong convergence in any event, of the main themes and categories developed from the data both within individual centres and also across the linguistic and cultural divide which separates UK health practice from that in France. On the contrary, many of the main issues commented upon in the two national reports were replicated in the findings of the other, which means that we may have some confidence that researchers on both sides of the channel have captured the essence of the phenomena described.

Equal numbers (22 each) of males and females were interviewed in the French arm of the study but women were under-represented in the UK patient sample, although there was an appropriate mix of White British/French and non-British/French respondents represented and the research methodology did not call for parity or stratification of the interview samples. The interview schedule originally developed in the UK was translated into French, so there may also be semiotic and cultural biases in the selection of words and phrases used although this is not apparent in the data presented. It is regrettable that the French report contains so little information about patient responses and for the most part, considers the views of healthcare professionals (in this case GPs), although this possibly balances out a bias in the opposite direction in the UK report.

It is acknowledged that the lack of homogeneity between the health care professional interviews conducted in the UK and France may pose a problem with regard to theoretical generalisation of the results, although comments from the 51 French GPs and smaller number of UK GPs were very similar in relation to all aspects of the discussion were noted and there were no apparent differences of opinion or experience in the two countries other than the greater publicly acknowledged role for GPs in relation to HIV prevention, testing and therapeutic follow-up after such a test (although many said this rarely occurred). In this case it was more important that the study reflect the realities of clinical practice in the clinical setting rather than methodological purity, although it would be extremely helpful in future studies to elicit the opinions of non-GP respondents amongst the professional sample.

## 6.0 Conclusions and recommendations

The project report has been prepared in the aftermath of the recent publication of a new EU Commission working document designed to support the implementation of a new action plan on HIV/AIDS in the EU and neighbouring countries (SWD(2014)106 final). This is complemented by an operational action plan that contains 50 actions structured in the following areas: (1) Politics, policies and involvement of civil society, wider society and stakeholders, (2) Prevention, (3) Priority regions, (4) Priority groups, (5) Improving knowledge, (6) Monitoring and evaluation (for more details see http://ec.europa.eu/health/sti_prevention/hiv_aids/index_en.htm).

Chief amongst the healthcare outcomes identified in the action plan is the need to 'improve the capacities and knowledge of medical staff and community based organisations with regard to HIV infection/co-infection (such as viral hepatitis and viral tuberculosis), prevention, testing, treatment and care, including the dissemination of best clinical practice'. In relation to priority groups, the action plan stressed the need to intensify the promotion of safer sex amongst men who have sex with men, improve information on HIV prevention, and better integration of sexual and reproductive health systems. It is envisaged that this will be achieved by intensifying voluntary counselling and testing programmes among men who have sex with men and similar at risk groups, including the encouragement of innovative testing strategies such as outreach and peer support mechanisms to promote early testing. More risk and harm reduction measures are posited for injecting drug users, whilst efforts to improve the health of migrant populations include targeted health promotion measures and improved access and treatment to services for this group of people. There is little mention however, how burgeoning rates of HIV infection in heterosexual patients who make up over half of the HIV positive population (both male and female) in both Kent and Medway, and Amiens and Creil are to be addressed. Nevertheless, the conclusions and recommendations are presented under these headings:

- Politics, improving policies, community and stakeholder engagement
- HIV Prevention strategies
- Priority areas for intervention
- Improving knowledge
- Monitoring and evaluation

Following a partner meeting in Amiens in December 2013 to discuss progress with stage 1 of the project, it was decided that any interventions developed should not address lengthy research objectives which require prolonged application periods for ethical approval, but should focus instead on pragmatic initiatives in these five areas which can be achieved quickly, the outcomes of which could be evaluated effectively as the basis for any scaled-up research projects in the future. It was acknowledged that priorities may vary slightly from centre to centre and country to country, so the proposals initially discussed at this and a further meeting in Kent in the spring of 2014 are not intended to be prescriptive but stimulate discussion about possible interventions for phase 2 at the next project partner meeting in June 2014.

### 6.1 Politics, improving policies, community and stakeholder engagement

HIV is a political issue. It is clear from our data that Kent and Medway have not been immune from the many changes in its prevalence within the region. Surprising perhaps, is the fact that heterosexuals form the majority of the HIV positive population in both areas. They are also more

likely, together with injecting drug users, to present late and thus incur additional substantive costs for health and social care providers. Hence the importance of using a cost-benefits approach when seeking to get buy-in to these initiatives from health service managers and external stakeholders is crucial. Any increase in early testing and diagnosis will have benefits for the healthcare system of any country, and not just the individual.

**6.2 Political action to raise public/professional awareness and support active HIV surveillance**

Given the apparent lack of engagement in HIV surveillance, testing and diagnosis within primary healthcare indicated in the UK data and the unwillingness of many in France to engage with the research, it is considered essential that new efforts are made to raise awareness of the benefits of early HIV testing in healthcare professions on both sides of the English Channel. This may involve militating for financial reimbursement for this work at local and national levels and where necessary, involving national and local community groups and the media in this process. Given that media exposure alone can raise awareness of the need for early HIV testing, it is suggested that the partners in the project consider how an orchestrated media campaign can be used to raise awareness of the benefits of early HIV testing. Few recommendations were made in the French report in respect of this although it is clear that health services are already working more closely with HIV charities in particular to improve recognition of HIV as a major health problem although individual relationships with other parts of the sector are doubtless also important.

**6.3 Policies and procedures to support active HIV surveillance and early testing**

Every clinical area should also be encouraged to have policies and procedures in place to identify those in need of an HIV test and the means to refer them for further support to recognised agencies. Apart from the support of nurses, medical staff and social workers; patients in the UK had little idea where to turn for support in some cases other than their local sexual health clinic, and few appeared to know that local authorities now have a duty of care to them since changes in the delivery of public health in England. There needs to be more integration between the NHS, charitable and local authority services in all areas of healthcare provision if they do not exist already. Within the UK, where HIV care is split ostensibly between GPs and sexual health clinics for the most part, there is need for regular communication to improve cooperation. A similar forum is held regularly between local authorities, healthcare providers and the charitable sector (namely hospices and care home providers) in respect of end of life and dementia care in Kent and Medway, and a forum of this kind should be considered as an urgent priority apart from any interventions designed for the clinical areas. The inclusion of staff from Kent County Council in the project to date has been commendable and it would be good to build upon these relationships to further expand this cooperation including perhaps, the development of interventions which would benefit both sectors.

**6.4 Changing the culture of NHS services towards HIV**

It is essential to change cultural attitudes towards discussion of sexual health and HIV risk in both countries. Frank open discussions about sexual health and risk behaviours should be a feature of healthcare consultations for all adults and indeed, adolescents notwithstanding their chronological age, presumed sexuality or outward appearance. We heard on many occasions (from both patients and healthcare professionals) that too many assumptions are made about people's sexual relationships and behaviours on conjecture or mere appearance alone. This was as likely to occur in France as in the UK where the question of sexuality was taboo for some of the GPs interviewed

because of its seeming too intimate or intrusive and there was evidence that some GPs associate homosexuality with moral deviancy as vividly illustrated in the qualitative data.

Healthcare providers must take a lead in changing social attitudes and mores in society which continue to stigmatise and force into the shadows those who are risk of HIV infection irrespective of their 'risk group'. Managers and senior clinicians in all settings should be exhorted to review their policies and procedures immediately, and if necessary, develop new ones in order to ensure that assessment of sexual health risk is as normal as asking someone about their familial cancer or diabetes risk. Medical practitioners should take a lead in this but the cultural change needs to span the remit of all professionals engaged in patient care. GP practices in particular need reminding that older people in particular would rather discuss such issues with their GP, but unless they provide an invitation and opportunity to have these conversations without embarrassment or feeling themselves to be a nuisance, this vulnerable cohort will continue to be diagnosed late and fail to benefit from treatment which may necessitate greater cost, both in terms of patient morbidity and mortality, and in healthcare expenditure. A healthy, happy sex life should be portrayed as a positive life-enhancing experience for everyone, including the elderly, and attempts to minimise embarrassment by inviting discussion about this should be positively encouraged in such settings, especially amongst older people and those who feel themselves to be stigmatised.

### 6.5 Review of testing and referral documentation, policies and procedures

We were surprised to learn during the course of the study that many areas still do not have policies or practices in place to identify those who might benefit from an early or expedited HIV test. These examples ranged from GP practices in the UK which lacked policies or procedures aimed at promoting conversations about a patients' sexual or reproductive health concerns and possible HIV risk factors on a regular basis (such as new patient consultations or where patients present with multiple opportunistic or viral infections) to acute hospitals which do not routinely ask for an HIV test to be conducted when testing blood for chlamydia or other sexually transmitted diseases when the route of transmission for each is the same. As previously mentioned, the French public health authorities explicitly recommend that primary health care professionals offer an HIV test to all patients between 15 and 70 years of age, irrespective of their risk of exposure to HIV (Ministry of Health and Sports, 2010). It would appear that better HIV surveillance and improved rates of early testing could be achieved by relatively simple changes to clinical documentation such as blood testing forms which are pre-checked or contain an aide memoire to this effect should any sexually transmitted or blood borne infection be suspected. It would be relatively easy to evaluate the impact of such a change now that a 5 year database of new diagnoses has been established as part of this phase one study both in terms of the number of diagnoses, but also the number of infections identified earlier.

Attention should also be paid to the ways in which services are delivered in some areas. Walking into a busy sexual health clinic may be difficult for many individuals, particularly the elderly or those who are socially inhibited by virtue of fear of recognition or stigma. They may however, be more receptive to attending a private appointment at certain times of the day when other groups or clinics are not running on the same premises. They may also value a confidential helpline or clinic telephone number so that their first encounter with the service can be via a more anonymous and less intimidating route. Stakeholder engagement could also include contact with local youth or LGTBQ organisations, churches, workplaces, sixth form colleges and employers to highlight the work

of local screening centres and reiterate the confidentiality of the services they offer. However, assumptions that GP services may offer a more sensitive or bespoke service to such clients is not borne out by the data, either in the UK or in France where feelings of stigma were just as likely to be expressed by patients cared for by their primary care physicians in the French health system.

### 6.6 Technological innovation

The Amiens meeting in December 2013 provided opportunity to discuss technological solutions to the problem of identifying HIV risk in those with unspecific and poorly defined health problems associated with HIV infection. It was suggested that the development of 'red flag' software to identify those likely to be at risk of contracting HIV or experiencing frequent unexplained illnesses could be developed, but these are costly and unlikely to work within different parts of the Leviathan NHS let alone internationally between France and the UK. They also run the risk of perpetuating the idea that HIV is a condition which only affects certain groups of people. It seems necessary therefore to develop whole systems approaches relevant to different health encounters in either country so that everyone exhibiting potential signs of HIV infection – or known to be at risk of contracting the illness is asked about their sexual health and automatically offered information on the benefits of early HIV testing.

It was agreed by all partners that renewed efforts should be made in both countries to raise the profile of HIV testing around World Aids Day at the beginning of December, and to work together to elicit the support needed for this purpose. In the meantime, the possibility of conducting an audit of all clinical areas to ascertain whether posters, leaflets and other sources of information are available and prominently displayed was discussed. Similarly, a simple screen saver application reminding staff to be alert to those patients whose presentation history is indicative of possible HIV infection might be more effective than complex integrated systems – especially in primary care settings and voluntary agencies or charities may be willing and able to help develop these.

### 6.7 HIV prevention strategies

Attempts to encourage early testing and diagnoses are laudable, but testing has no preventative value. Closely aligned to, but separate from the above therefore, would be the development of a pilot outreach project which identifies target groups or areas of local concern and provides free condoms, lubrication etc. as well as information about safer sex and HIV testing to targeted groups of individuals in places where they associate such as shopping malls, supermarkets, pubs, clubs, bars, schools, universities etc. We were impressed by the use of a converted double decker bus for such purposes by Kent Community Health NHS Trust on World Aids Day in Canterbury, and this is also used by other healthcare providers such as Maidstone and Tunbridge Wells NHS Trust. We regard it as essential however, that projects such as this are initiated, continued and extended in both France and the UK, with particular emphasis on preventative work including the targeting of people accessing the night-time economies of our main towns and cities and it is regrettable that one such request to Canterbury City Council in Kent was not taken up by the Council. These are more likely to reach younger sexually active adults who might be engaging in multiple sexual encounters for the first time and less inhibited in doing so as a result of alcohol consumption or peer pressure.

Activities of this nature could be used to promote HIV prevention and promote awareness of the benefits of early testing by visiting local schools, youth clubs and sports centres/events as part of a targeted health promotion project for young people in the region. They could of course be used as

well to promote HIV testing, but the health promotion message should also be an integral part of such outreach attempts. One patient mentioned a very successful initiative at Leyton Orient Football Club which was run precisely on these lines and helped to de-stigmatise HIV in using peer pressure/support in a very positive and encouraging way. Centres could also look at joining together to launch media and social advertising campaigns, discussions on local radio and TV stations about the benefits of early testing which would also attract an older cohort of people.

**6.8 Priority areas for intervention**

It is clear from both the UK and French data that many respondents feel an acute sense of stigma and many fear rejection when diagnosed with HIV. Some – particularly older people would rather access healthcare in less stigmatising locations than a sexual health clinic, although in France where people access such services through their GPs, there is evidence that some still feel stigmatised and marginalised. Others even feel that they may be judged negatively by their GP because of moral judgements about their sexual relationships. In the UK, many patients said that they would much prefer talking to their GP although some had concerns about confidentiality, particularly in smaller rural areas where they may know or meet other members of the GPs staff socially or informally. Others were also worried about their HIV status being on their official medical record.

Common assumptions that HIV is a condition affecting young people (predominantly men who have sex with men or immigrants from African, Caribbean, some Asian or eastern-European countries) must therefore be challenged. Many of the respondents in the study were in their late 40s, 50s and 60s and the oldest in both countries were in their 70s and 80s. Furthermore, contrary to popular myth, the majority of those diagnosed with HIV in both countries were heterosexual, so consideration must be given to ways in which the positive benefits of early HIV testing (and of HIV risk in this group) can be conveyed to the majority heterosexual population in Kent and Medway, and in Picardy, and in particular to women and older adults who are more likely to be diagnosed late in comparison to other groups.

There is perhaps a role for greater intervention using voluntary agencies including churches and faith groups, social clubs and other sources of peer support to eradicate the stigma associated with HIV in older cohorts and promote the benefits of early testing, particularly for those engaging in new sexual relationships following a divorce or the death of a lifelong sexual partner. The very positive and supportive help provided by an occupational health physician in at least one instance should also alert us to the fact that opportunities for intervention in the workplace also exist, and occupational health practitioners should definitely be encouraged to see a greater role for themselves in this regard although anxiety about employee confidentiality are bound to arise.

Consideration also needs to be given to other options for testing, including making self-test kits freely available in pharmacies and other locations such as fitness centres, bars, clubs, university health centres etc. The availability of free self-testing kits is currently very limited and they can be expensive to purchase privately. The Terence Higgins Trust in the UK for instance, only make them available to men who have sex with men and ethnic minority groups perceived to be at greater risk, but these attitudes and the easy availability of such kits (from whatever source) must be increased for those who would prefer to undertake an initial test in the privacy of their own homes. Consideration should be given perhaps, to making these available via a confidential postal service from sexual health clinics, GP practices, or a confidential helpline with subsequent consultation if

necessary. In the UK, the remit for such activities now lies with local authorities in their public health role, which should be expanded to meet need in minority groups know to be at additional risk. In France rapid testing is provided freely in the community, in bars for example, by the HIV charity AIDES. It is also provided anonymously and free of charge by healthcare professionals working out of healthcare centres, including free testing for hepatitis for those living in temporary accommodation such as homeless shelters and worker's accommodation which should be encouraged.

### 6.9 Improving knowledge

All of the respondents old enough to remember the public health campaigns conducted in the UK during the 1980s and 1990s have vivid memories of these, and whilst most would not want to see a return of the very negative and sometimes stigmatising messages conveyed then, most feel that there is a dearth of accurate information in the media about HIV at present. This is also a sentiment raised by French partners and respondents. Almost everyone asked, irrespective of nationality stressed that they would like to see more and clearer public health messages targeted at the general population as well as those perceived to be at additional risk, and there was a strong feeling that the new social media and public health campaigns are needed given what is now known about the needs of those living in the two regions covered by the study and the benefits of early testing. Other opportunities to improve the knowledge of the general population have already been addressed in the above sections in relation to prevention and screening.

Data from the French arm of the study shows that there is a clear need for information about transmission risk and the benefits of early detection to be made available to those who judge themselves to have been at risk, but they will not know this if they are not fully aware about the true extent of the risk. Worryingly, most of the GPs interviewed in France demonstrated poor knowledge about HIV/AIDS and many said that they did not know enough about the disease, current patterns of transmission and the benefits of early testing and treatment. Training activities including continuing medical education should be implemented to improve the knowledge of those specifically charged with the prevention and diagnosis of HIV in that country, but planned events in the Picardy region in the past have received little coverage or attention with poor attendance. Suggested improvements would include the inclusion of HIV in other, less specific sessions to overcome ennui and perceptions that HIV is not a problem which specific GPs are likely to face in their careers or geographical areas. It has also been suggested that skilled mentors support those newer to this public health role.

This view was equally prevalent in the UK data in which the need for better education and training of healthcare professionals (particularly GPs) about HIV was cited most commonly as the single most important factor likely to lead to recognition of early signs of the infection and increasing the early uptake of testing. In the UK too, respondents said that additional communication skills training and insight into the specific needs of those affected by HIV should also be improved. Many, including those GPs interviewed, felt that all patients should be tested at least once when joining a new practice as part of a general health consultation and at other key moments in their health journey as (for example) when being admitted to hospital with any acute and unexplained condition. This requires the up-skilling of a large proportion of the workforce, initially through continuing professional development but ideally prior to entry to the profession as part of their regulatory training and registration. In the first case, it may be advisable to consult with external stakeholders such as Medical Deaneries and funding bodies such as Health England Kent, Surrey and Sussex about funding for short courses which can be developed, delivered and evaluated relatively easily. These

should be aimed primarily at GPs and those working in acute areas as they seem to be the areas of greatest need. As in France, it is acknowledged that getting 'buy-in' from practitioners who are extremely busy may be challenging, hence the need to consult with local professional bodies/agencies and also consider remuneration for time spent accessing such training days since there is a clear policy emphasis for this in both countries as a result of the EU recommendations discussed at the start of this section which provide adequate support for the second phase of the study.

## References


Adler, A., Mounier-Jack, S. and Coker, R.J. (2010) Late diagnosis of HIV in Europe: definitional and public health challenges. *Health Sciences*, 21:284-293.

Branson, B.M., Handsfield, H.H., Lampe, M.A., Janssen, R.S., Taylor, A.W., Lyss, S.B., and Clark, J.E. (2006) Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. *Morbidity and Mortality Weekly Report,* 55:1-17.

Camoni, L., Raimondo, M., Regine, V., Salfa, M.C. and Suligoi, B. (2013) Late presenters among persons with a new HIV diagnosis in Italy, 2010-2011. *BMC Public Health,* 13:281.

Carricaburu, D. and Ménoret, M. (2004) *Sociologie de la santé*. Montparnasse: Armand Colin.

Castilla, J., Sobrino, P., De La Fuente, L., Noguer, I., Guerra, L. and Parras, F. (2002) Late diagnosis of HIV infection in the era of highly active antiretroviral therapy: Consequences for AIDS incidence. *AIDS*, 16:1945-1951.

Chadborn, T. (2006) The late diagnosis and consequent short-term mortality of HIV-infected heterosexuals (England and Wales, 2000-2004). *AIDS,* 20:2371-2379.

Creswell, J.W. and Plano Clark, V.L. (2011) *Designing and Conducting Mixed Methods Research.* Thousand Oaks, Sage.

Dowson, L., Kober, C., Perry, N., Fisher, M. and Richardson, D. (2012) Why some MSM present late for HIV testing: a qualitative analysis. *AIDS Care,* 24:204-209.

European Centre for Disease Prevention and Control (2011) HIV/AIDS surveillance in Europe 2011. Brussels: European Centre for Disease Control and World Health Organisation.

Garcia de Olalla, P., Manzardo, C., Sambeat, M.A., Ocana, I., Knobel, H., Humet, V., Domingo, P., Ribera, E., Guelar, A., Marco, A., Belza, M.J., Miro, J.M. and Cayla, J.A. (2011) Epidemiological characteristics and predictors of late presentation of HIV infection in Barcelona (Spain) during the period 2001-2009. *AIDS Research and Therapy*, 8:22.

Girardi, E., Sabin, C. and d'Arminio Monforte, A. (2007) Late diagnosis of HIV infection: Epidemiological features, consequences and strategies to encourage earlier testing. *Journal of Acquired Immune Deficiency Syndrome*, 46 (Supp 1):3-8.

Goffman, E. (1963) Stigmate, les usages sociaux du handicap, Editions de minuit.

Goffman, E. (1968) Asiles. Etudes sur la condition sociale des malades mentaux, Editions de minuit.

Hanf, M., Bousser, V., Parriault, M.C., Van-Melle, A., Nouvellet, M., Adriouch, L., Sebillotte, C. G., Couppie, P. and Nacher, M. (2011) Knowledge of free voluntary HIV testing centres and willingness

to do a test among migrants in Cayenne, French Guiana. *AIDS Care*, 23:476-485.

Institute of Health Surveillance/l'institut de veille sanitaire (2014) Dépistage du VIH en France. BEH 2014 no 32-33.

Institute of Health Surveillance/l'Institut de veille sanitaire. (2012) HIV/AIDS Statistics for 2012. http://www.aides.org/actu/france-6-372-personnes-ont-decouvert-leur-seropositivite-au-vih-en-2012-2353.

Johnson, M., Sabin, C. and Girardi, E. (2010) Definition and epidemiology of late presentation in Europe', *Antiviral Therapy*, 15 (Supp 1):3-8.

Krentz, H.B., Auld, M.C. and Gill, M.J. (2004) The high cost of medical care for patients who present late (CD4 <200 cells/mm³) with HIV infection. *HIV Medicine*, 5:93-98.

L'agence régionale de santé de Picardie et du conseil régional de Picardie (2014) Sida et infection par le VIH en Picardie. Amiens: Observatoire Régional de la Santé et du Social de Picardie.

Lert, F. and Pialoux, G. (2010) Numéro thématique – L'infection à VIH-sida en France en 2009: dépistage, nouveaux diagnostics et incidence. *Bulletin épidémiologique hebdomadaire, no.* 45-66:449-476.

Lo, Y., Wu, P., Hsieh, C., Chen, M., Shen, W., Hsieh, S., Sun, H., Liu, W, Hung, C. and Chang, S. (2011) Late diagnosis of Human Immunodeficiency Virus infection in the era of highly active Antiretroviral Therapy: role of socio-behavioural factors and medical encounters. *Journal of the Formosan Medical Association*, 110:306-315.

Ministère de la santé et des sports (2010) *Plan national de lutte contre le VIH et les IST 2010-2014*. Paris: Gouvernement de la République française.

Mukolo, A., Villegas, R., Aliyu, M. and Wallston, K.A. (2012) Predictors of Late Presentation for HIV Diagnosis: A Literature Review and Suggested Way Forward. *AIDS and Behaviour,* 17:5-30.

Pereira, G., de Souza, S., Caetano, K., Martins, R., Gir, E., Minamisava, R., Gomes, J. and Teles, S. (2011) 'Late HIV diagnosis and survival within 1 year following the first positive HIV test in a limited-resource region. *Journal of the Association of Nurses in AIDS Care.* 22:313-319.

Public Health England (2013) *HIV in the United Kingdom: 2013 Report*. London: Public Health England.

Public Health England (2014) The surveillance and epidemiology of human immunodeficiency virus (HIV). 31st July 2014 (https://www.gov.uk/government/collections/hiv-surveillance-data-and-management) accessed 26th November 2014.

Rashbrook, E. (2013) *HIV Prevention Needs Assessment for London.* London: Public Health England.

Schwarz, S., Richards, T.A., Frank, H., Wenzel, C., Hsu, L.C. Chin, C.J., Murphy, J. and Dilley, J. (2011) Identifying barriers to HIV testing: personal and contextual factors associated with late HIV testing. *AIDS Care*, 7:892-900.

Siegel, K. and Krauss, B. (2004) Living with HIV Infection: Adaptive Tasks of Seropositive Gay Men. *Journal of Health and Social Behavior*, 32 (3), 1991, pp.17-32, cited in Carricaburu, D. and Ménoret M. (2004) *Sociologie de la santé*. Montparnasse: Armand Colin.

Silverman, D. (1989) Making sense of a precipice: constituting identity in an HIV Clinic pp101-126. In Aggleton, P., Hart, G. and Davies, P. *AIDS: Social Representations, Social Practices.* London: Routledge.

Souville, M. (2002) Le savoir et le risque: appropriation et adaptation des connaissances en médecine générale. *Sociétés*, 3(77):21-36.

Sudarshi, D., Pao, D., Murphy, G., Parry, J., Dean, G. and Fisher, M. (2008) Missed opportunities for diagnosing primary HIV infection. *Sexually Transmitted Infections*, 84:14-16.

Sullivan, A.K., Curtis, H., Sabin, C.A. and Johnson, M.A. (2005) Newly diagnosed HIV infections: review in the UK and Ireland. *British Medical Journal*, 330:1301-1302.

Terence Higgins Trust (2013) HIV postal test. http://www.tht.org.uk/sexual-health/HIV-STIs/HIV-AIDS/HIV-postal-test (Accessed 12th February 2014).

Thiaudière, C. (2002) Sociologie du sida, La découverte.

UNAIDS (2012) Global Report: UNAIDS Report on the Global AIDS Epidemic 2012. http://www.unaids.org/sites/default/files/media_asset/20121120_UNAIDS_Global_Report_2012_with_annexes_en_1.pdf accessed 26th November 2011.

Weitz, R. (1989) Uncertainty and the lives of persons with AIDS. *Journal of Health and Social Behavior* 30: 270-281, cited in Carricaburu, D. and Ménoret, M. (2004) *Sociologie de la santé*. Montparnasse: Armand Colin.

Weitz, R. (1990) Living with stigma of AIDS. Qualitative Sociology, 13:23-28, cited in Carricaburu, D. and Ménoret, M. *Sociologie de la santé.* Montparnasse*:* Armand Colin.

World Health Organisation (2007) Guidance on provider-initiated HIV testing and counselling in health facilities. Geneva: World Health Organisation.

WHO/UNAIDS/UNICEF (2011) *Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access 2011*. http://www.who.int/hiv/pub/progress_report2011/en/ accessed 26th November 2011.

Wohlgemut, J., Lawes, T. and Laing, R.B. (2012) Trends in missed presentations and late HIV diagnosis in a UK teaching hospital: a retrospective comparative cohort study. *BMC Infectious Disease*, 28:12:72. doi: 10.1186/1471-2334-12-72.

Yazdanpanah, Y., Lange, J., Gerstoft, J. and Cairns, G. (2010) Earlier testing for HIV – how do we prevent late presentation?. *Antiviral Therapy,* 15(Supp 1):17-24.

**Websites:**
http://ec.europa.eu/health/sti_prevention/hiv_aids/index_en.htm accessed 6th June 2014
http://www.avert.org/european-hiv-aids-statistics.htm#footnote1_mxb276j accessed 26th November 2014.

## Appendix 1: Main Data Collection Topics for Review of Patient Records

Patient Identification Number/Reference ……

| **Data Item** | **Options (where applicable) and *instructions*** |
|---|---|
| Clinical setting where notes held | MTW – Rubin Clinic, GUM Services<br>Medway – GUM Department, Green Zone<br>KCHT – The Gate, K&C Hospital, Canterbury<br>KCHT – William Harvey Hospital, Ashford<br>KCHT – Royal Victoria Hospital, Folkestone<br>KCHT – The Riverside Clinic, Gravesend Community Hospital<br>KCHT – Minnis Bay Clinic, QEQM, Margate |
| Patient Identification Number/Reference | *Free text* |
| Date of Birth | *In YYYY/MM/DD format* |
| Gender | Male<br>Female |
| Ethnic Status | White British<br>White Irish<br>Asian/Asian British<br>Black/African/Carribbean/Black British<br>Mixed ethnic backgrounds (e.g. White and Asian)<br>Other ethnic group |
| Education | Secondary education<br>Further education<br>Higher Education |
| Occupational status | Employed full-time<br>Employed part-time<br>Unemployed<br>In education/training<br>Retired |
| Current or most recent employment | *Free text* |
| Current or most recent employment coded | Unskilled manual including service and retail<br>Skilled manual<br>Office/routine administrative work<br>Managerial or supervisory<br>Professional |
| Country/Region of birth | United Kingdom<br>European Union<br>Rest of the world |
| Current postcode | *Inserted without a space e.g. TN317FL* |
| Transmission group *(MSM, IDU, etc.)* | MSM<br>IDU<br>Heterosexual<br>Other (*free text*) |
| Date of first positive HIV test | *In YYYY/MM/DD format* |
| Age when diagnosed with HIV | *Enter in whole years* |
| Circumstances or Place of first test | GUM clinic<br>On hospital admission due to illness |

| | |
|---|---|
| | Ante-natal screening<br>Other |
| History leading up to diagnosis | *Free text – any information in the notes regarding the background to the patient being diagnosed* |
| CD4 count at diagnosis | *The figure recorded in the notes* |
| Estimated date of infection/ exposure to risk | *In YYYY/MM/DD format* |
| Age at date of infection | *Enter in whole years* |
| Relationship status at the time of infection | Single<br>Married<br>Civil Partnership<br>Cohabiting<br>Separated<br>Divorced<br>Widowed |
| Number of children | *Enter number* |
| Registered with GP | Yes<br>No |
| Co-morbidities recorded in the notes at the time of diagnosis – AIDS defining | Respiratory<br>Gastronenterology<br>Neurology<br>Dermatology<br>Oncology<br>Gynaecology<br>Ophthalmology<br>None |
| Co-morbidities recorded in the notes at the time of diagnosis – other conditions | Respiratory<br>Gastronenterology<br>Neurology<br>Dermatology<br>Oncology<br>Gynaecology<br>Haematology<br>Ophthalmology<br>ENT<br>Other<br>None |

## Appendix 2: Patient Interview Topic List

### Can you tell me what you knew about HIV before discovering that you were HIV positive?

What was your understanding of the disease
Where did you get your knowledge about it
Did you feel that HIV was relevant to you?

### How long have you known that you were HIV positive?

*How long before taking the HIV test were you worried you might be HIV+?*
*(if they did not think they would be ask if they had previously heard of HIV testing before their test)*
*Do you have any idea what circumstances or situation would have put you at risk of being infected with HIV?*

### Who made the decision that about having an HIV test?

*What happened in the lead up to you deciding to take an HIV test?*
*What triggered you to have a test?*
*What happened in between deciding to go and going for the test?*
*What was going through your mind?*
*Did you decide on your own to take the test?*
*Did anyone convince you to do it? If yes, who (a relative, friend, acquaintance, professional) and how did it come about?*
*Did anything prevent you from having/asking for a test earlier?*

### Following the decision to have the test how long did you wait to actually take it?

*What were you feeling at this time?*
*What factors influenced the timing of going for a test?*
*Did you talk about going for a test with anyone?*

### Did you know who or where to ask for an HIV test?

*How did you know where you could get an HIV screening test?*
*Had you seen any advertising about HIV testing in the community or in the media?*

### If you could turn back the clock is there anything about the process leading up to your test that you would change?

*What advice would you give to others in the same situation as you?*

### Is there anything about the HIV testing process that you would change If so, how?

### If you were asked, to come up with three main suggestions about how the NHS could persuade people to seek HIV testing earlier, what would they be?

### Is there anything that you would like to add?

## Appendix 3: Health Professional Interview Topic List

**Could you tell me briefly what you know about HIV infection?**

*Is it something you come across with your patients?*
*What sort of patients do you feel may be at risk of HIV infection?*

**What kind of factors or symptoms would trigger/lead you to think about HIV testing?**

**Have you ever had to refer a patient for HIV testing or offered them a test?**

*If yes what symptoms or other factors triggered the referral and how did you go about it?*
*If no what do you think might be your course of action if you came across a patient who you felt might have HIV*
*How did the patient react and what effect did this have on your actions?*

**Do you consider you have a role to play in the detection of HIV?**

*If yes what would it be and if no what are your reasons*

**Is there a policy/process in your surgery or clinic that covers HIV testing?**

**How would you feel about broaching the issue of HIV testing with your patients?**

**Have you ever had a patient who has voluntarily ask you for an HIV test?**

*What have you done following this request*

**What sort of obstacles/barriers do you think might prevent a patient from asking you for a test?**

**What sort of obstacles could prevent you from offering a test?**

**In your professional experience, do you think that patients are adequately informed about the possibility of undergoing an HIV test as part of their clinical care?**

**Do you feel you have enough the skills and knowledge and understanding of HIV to be able to respond to patients who need a HIV test?**

**Additional topics for General Practitioners only**

**For the HIV patients registered in your practice, do you think there were opportunities where HIV infection could have been diagnosed earlier?**

*What suggestions do you have in terms of earlier diagnosis?*

**To what extent are you involved in the prevention of HIV?**

*Are you aware of any regional or national initiatives regarding your HIV prevention?*
*Do you have any posters or literature on HIV or HIV testing in your waiting/consulting room?*
*Does your surgery provide condoms to patients if available or requested?*

**Is there anything that you would like to add?**

**Demographic data on respondent**

*Speciality*
*Year qualified from medical school*
*Age*
*Gender*

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